

Authors

Dr Sharon Andrews

Associate Professor Fran McInerney

Ms Susan Leggett

Ms Cathy Donohue

Professor Andrew Robinson

Dementia-Palliative Care Resource Nurse Resource Kit



August 2011

Funded by the Australian Government Department of Health and Ageing

WICKING
DEMENTIA RESEARCH
& EDUCATION CENTRE

M+ | Menzies
Research
Institute


Australian Government
Department of Health and Ageing

 **ACU**
AUSTRALIAN CATHOLIC UNIVERSITY

UTAS 

Project Team

Project Leader: Dr Michael Ashby, Professor of Palliative Care, University of Tasmania, Director of Palliative Care, Royal Hobart Hospital, and Honorary Fellow, WDREC, Menzies Research Institute Tasmania.

Tas manager: Dr Andrew Robinson, Professor of Aged Care Nursing, School of Nursing and Midwifery, and Co-Director, Wicking Dementia Research and Education Centre, Menzies Research Institute Tasmania.

Vic manager: Dr Fran McInerney, Associate Professor of Aged Care, School of Nursing and Midwifery, Faculty of Health Sciences, ACU/Catholic Homes and Honorary Associate, Wicking Dementia Research and Education Centre.

Project coordinator: Dr Sharon Andrews, Research Fellow, Wicking Dementia Research and Education Centre, Menzies Research Institute Tasmania.

Evaluation specialist: Dr Christine Stirling, Senior Research Fellow, Wicking Dementia Research and Education Centre, Menzies Research Institute Tasmania.

Expert consultancy: Dr Chris Toye, Associate Professor, Older Persons' Health Care, Curtin University of Technology, Adjunct Senior Lecturer, School of Nursing and Midwifery, UTAS.

Tas Project officers: Ms Susan Leggett, Research Associate, Wicking Dementia Research and Education Centre, Menzies Research Institute Tasmania.

Vic Project officers: Ms Cathy Donohue and Ms Michelle Morgan, Research Assistants, Aged Care, School of Nursing & Midwifery, Faculty of Health Sciences, ACU

Research Assistant: Mr Carl Higgs, Research Assistant, Wicking Dementia Research and Education Centre, Menzies Research Institute Tasmania.

Acknowledgements

The development of this resource was funded by the Australian Government Department of Health and Ageing, Local Palliative Care Grants Program, Round Five.

For further information please contact Dr Sharon Andrews, Project Co-Ordinator: sharon.andrews@utas.edu.au

Contents

Introduction	4
About this resource	7
1. Setting up	8
1a. Establish partnership with knowledge translation collaborators.....	8
1b. Consider barriers and enablers to establishing and developing the DPRN program .	9
1c. DPRN recruitment.....	12
2. DPRN preparation	13
3. Building support and engagement.....	14
3a. Action Groups.....	14
3b. Practice Development Network	15
3c. Awareness raising.....	16
Attachments.....	17
References	21

Introduction

In Australia over half (53%) of the people living in Residential Aged Care Facilities (RACFs) have some type of dementia.¹ Of these people, 87% require “high-level” care.² It is estimated that in 2008-09 around 88% of residents separated from Australian RACFs via death, a rise from 78% in 1998-99.¹ These statistics reflect the increasing acuity of residents in RACFs over the past decade. During this period of time there has also been growing recognition in the literature that dementia is a terminal condition.³⁻⁴

A palliative approach to care is advocated as a framework to enhance quality of life for people with advanced dementia, alleviate distressing symptoms, and avoid unnecessary and burdensome hospitalizations and associated medical interventions.⁵⁻⁸ A palliative approach is proactive and responsive to the needs of people with any life-limiting or life-threatening illness and their caregiver/family and focuses on holistic assessment and care provision, that acknowledges the physical, psychological, social, and spiritual dimensions of the person.⁹⁻⁴² A palliative approach is predicated on the open acknowledgement of dying and death as an integral part of life.⁵ For people with advanced dementia, its implementation is facilitated by family and health care professionals recognizing that dementia is a terminal condition³⁻³⁸ and engaging in collaborative and proactive discussions about the person’s condition, prognosis and future wishes for care.¹⁰⁻¹²

Since the 1990s there has been a greater recognition of the need to improve the provision of palliative care for people with non-malignant conditions such as dementia. The development of the *Guidelines for a Palliative Approach in Residential Aged Care Facilities*³⁹ demonstrates more focused attempts to integrate a palliative approach within RACFs. However, the translation of evidence into practice to improve the provision of palliative care for people with dementia is complex and aged care staff face a range of contextual challenges. For example, in residential aged care facilities (RACFs), staff play a pivotal role in initiating dialogues with family caregivers about the dementia trajectory, advance care planning and end of life care planning. However is both complex and challenging for RACF staff.¹³ There is evidence that RACF staff require further education around key aspects of dementia and related principles of contemporary palliative care.^{7,14-15} Moreover, staff have reported feeling unprepared to discuss with family caregivers issues about death and dying for residents with dementia.^{14,7}

One approach to addressing issues of staff capacity to deliver evidence-based approaches to care has been the establishment of a “clinical champion” role in RACFs.¹⁶⁻¹⁹ This role has also been referred to as a “link nurse” or “resource nurse”.

A link or resource nurse has been described as an individual in a care environment who, supported by other practitioners (for example, clinical nurse specialists), will be able to act as a local resource and disseminate information and learning within the setting.¹⁸ This type of role has been used in other research to enhance evidence-based practice across a number of target areas (e.g., wound care, infection control, palliative care, pain management).^{17-18,20-24} Link nurses may be supported by members of a specialist care team or service. Hence the link nurse is an important intermediary, providing two-way communication between the specialist team and their own clinical area.^{20,22} Through these connections with specialist services, the link nurse role has a primary aim of enhancing clinical effectiveness and evidence-based practice within a given area.²¹ Staff members taking on this role should have knowledge of the area, be able to support and

educate other staff and be in a position to implement change.^{23,25} It has been suggested that the link nurse model is an effective strategy for the dissemination of information to and education of nursing staff.^{18,22,24} In the context of dementia care and palliative care, link nurse initiatives have been suggested by a number of studies to foster knowledge translation within local settings and support an evidence-based change agenda.^{17-18,22-23,26}

The *Dementia Care Dialogues* Project

This Resource Kit has been developed as an outcome of a research project titled *Dementia Care Dialogues* (full title: Opening a dialogue: Improving communication and practice in advance care and end of life care planning). The *Dementia Care Dialogues* project was conducted across four RACFs, two in Tasmania and two in Victoria. The overarching aim of the project was to improve communication between Residential Aged Care Facility (RACF) staff and family caregivers about dementia as a terminal condition, a palliative approach and issues related to advance care planning. The development of a *Dementia–Palliative care Resource Nurse* (DPRN) role in each participating RACF was a key intervention of the project. For further information about the project, log on to <http://www.caresearch.com.au/caresearch/tabid/1533/Default.aspx>.

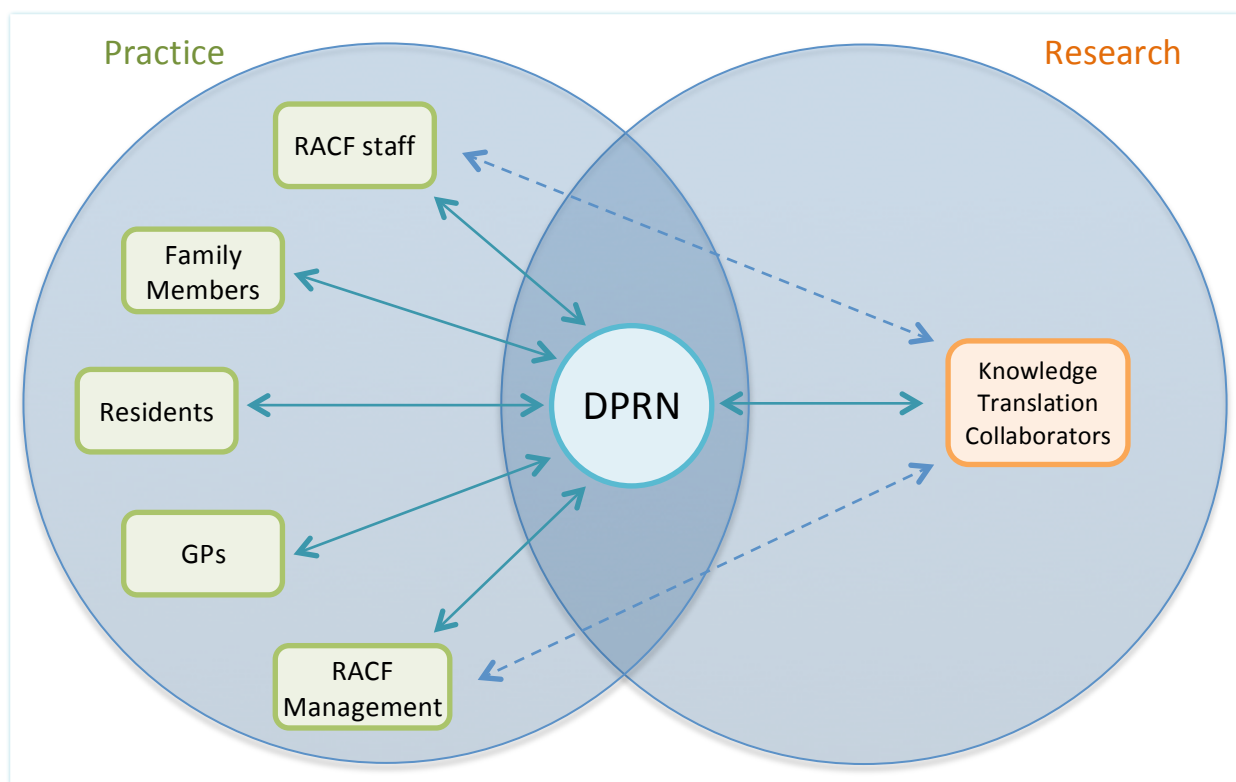
The DPRN role was based on a “link nurse” model, however we chose the term “Dementia–Palliative care Resource Nurse” rather than “link nurse” for a number of important reasons. Firstly, our project had an explicit focus on building capacity and enhancing in-house expertise of key staff members who had identified themselves and/or been identified by management as potential clinical leaders. The principal role of the DPRNs was to be a local resource person at the RACF in the area of palliative care for people with dementia. Hence, this role was best captured by the term “resource nurse”. While an important aspect of the role was to build networks with specialist palliative care and aged/dementia care services—which certainly resonates with descriptions of other “link nurse” roles—our program was largely predicated on the resource nurses engaging in a process of knowledge translation with professionals who had expertise in this area. Hence, the resource nurse was a key player in the “translational space”.

The DPRN role in summary

In summary, the Dementia–Palliative care Resource Nurse:

- aims to enhance clinical effectiveness and the implementation of research findings in clinical practice;
- acts as a local resource to disseminate information and learning within the setting;
- is supported and facilitated by members of a specialist care team or service; and
- provides two-way communication between the specialist team and their own clinical area.

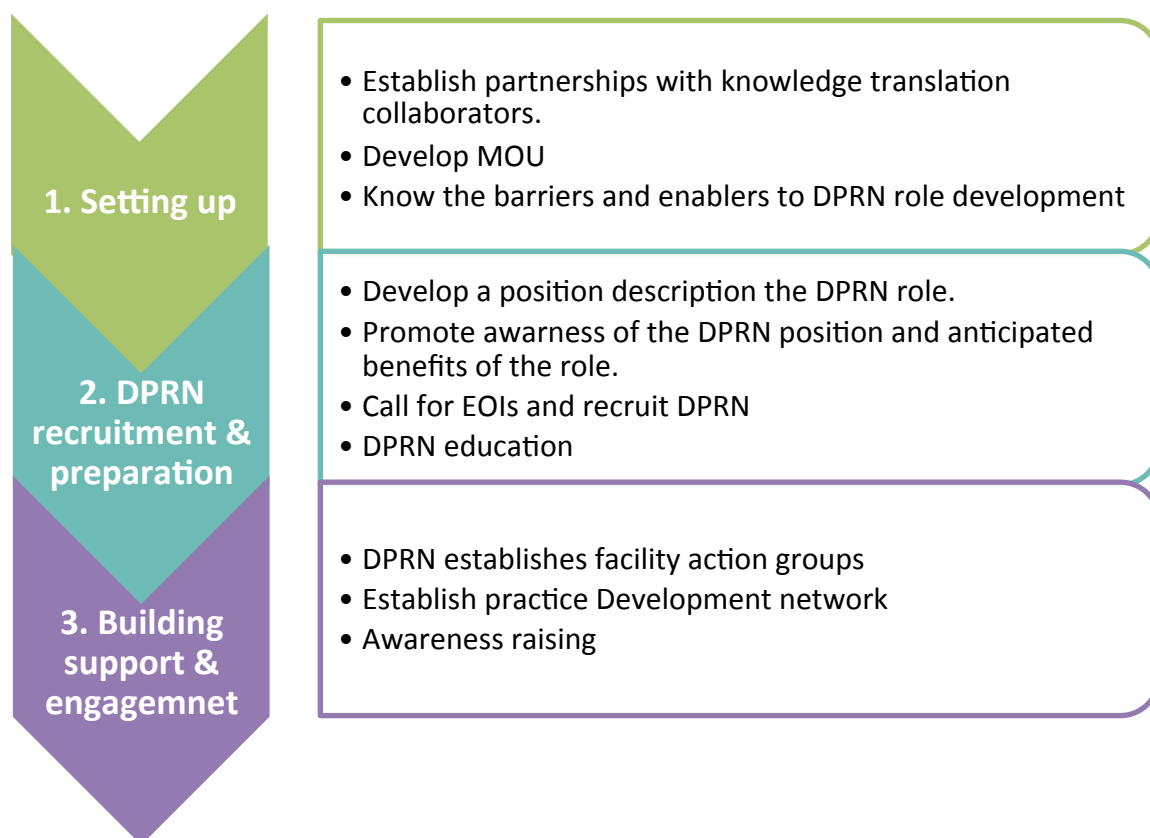
Figure 1 – a diagrammatic representation of the DPRN role.



About this resource

This Resource Kit has been designed as a guide to aid the implementation of the DPRN role in Residential Aged Care Facilities (RACFs). It is a starting point for RACF staff who wish to implement this role in their facility. Preparation is crucial to setting up this role and in recognition of this important factor, this resource details three key steps in establishing a DPRN role (see figure 2).

Figure 2 – Model for establishing the DPRN role



1. Setting up

1a. Establish partnership with knowledge translation collaborators

As a first step to setting up a DPRN role in a RACF, a collaborative partnership between the aged care organisation and a knowledge translation agency such as a university department, which has the capability to support aged care providers to develop evidence-based practice, should be established. The development of a formalised partnership should ideally involve a Memorandum of Understanding (MOU). The MOU should clearly establish how the partnership will practically function along with each party's responsibilities.

Below are some suggested expectations for aged care providers in setting up a DPRN role which could be included in an MOU:

- Support for the nomination of a suitable staff member to assume the DPRN role.
- Facilitate DPRN to attendance at education sessions (via rostering, backfill, etc.).
- Support DPRN to collect data to identify education/training needs of RACF staff with whom the DPRN will work.
- Support for DPRN to undertake their role through regular "quarantined" time each week (e.g., via rostering, funded time).
- Support engagement of the DPRN with knowledge translation collaborators to implement evidence into practice.
- Support the DPRN to establish action group(s) of interested staff to assist in knowledge translation activities (e.g. provide a venue for meetings, assist with rostering so that staff can attend meetings with DPRN).
- Support the development of cross-sectoral communication and relationship building to strengthen the sustainability of the DPRN role.
- Agree upon a communication strategy with the DPRN

Some suggested expectations for the agency with expertise in knowledge translation would include:

- Provide a contact person(s) to work with the DPRN, who has expertise in aged/dementia care and knowledge translation to support the development of strategies to build evidence-based practice palliative care for people with dementia (e.g: staff education, mentoring, cross-sectoral stakeholder engagement, resource development).
- Facilitate the DPRN to access to evidence-based information relevant to their role development.
- Provide preparatory education for the DPRN about dementia, palliative care and knowledge translation.
- Provide the DPRN with assistance to analyse local data to identify education/training needs of staff and other stakeholders.

1b. Consider barriers and enablers to establishing and developing the DPRN program

When setting up a DPRN program it is important to be aware of the potential barriers and enablers to establishing this role. This will help with selecting the right person for the position and setting up conditions within the program to support the role. Consideration of the barriers and enablers with respect to the local circumstances is paramount to setting up a program that will have an “organisational fit”. In this section, the barriers and enablers identified in the literature in relation to link nurse programs and from our experience are outlined.

Enablers

Box 1: Summary of Enablers

- Personal traits (e.g., motivation, enthusiasm, desire to improve skills and practice)
- Clarity of roles and responsibilities
- Clearly articulated management expectations of the position
- Formalised resource nurse role with paid time—having quarantined time
- Management support to attend education initiatives
- Management support that facilitates the role development
- Pathway for career advancement

The importance of personality and a number of attitudes of those undertaking a resource nurse role has been emphasized.²⁵ These include but are not limited to:

- a personal interest in the area (e.g., dementia and palliative care);
- a desire to improve the practice and skills of both self and colleagues;
- motivation and enthusiasm for the role;
- finding the area of work to be a rewarding and relevant;
- an interest in extending professional practice; and
- personal traits of being approachable, a good listener, assertive, empathetic, open-minded, non-paternal and diplomatic.

Clarity of roles and responsibilities for the staff member taking on a resource nurse role is also important for successful implementation.³¹ Hence it is invaluable to provide a detailed position description that outlines:

- roles and responsibilities;
- expected work hours; and
- expectations from management for the role.

The timing of educational initiatives around shift-work is another important enabler to the development of the resource nurse role²¹ that is central in maintaining the link nurse participant’s motivation. The location of education sessions in, or close to, the workplace has been found to aid attendance and success of training.^{22,32-33}

Management support for the establishment and development of the role is crucial to its implementation. Hence, for long-term success of link nurse programs the link nurse role needs to be formalised, with allocated paid time for the duties involved, and a clear pathway for career advancement.³¹

DPRN perspectives on the importance of manager support

'The Director of Care ... [has] always been supportive...has been excellent ...she's very approachable and she's always really put herself out... [X] would be my first port of call and she's been [a] great support'.

Our evidence strongly indicates that a DPRN should:

- Be a Registered Nurse;
- Have a level of seniority or authority within the facility, ideally in a senior clinical role, and function as a clinical leader in the RACF;
- Have previous experience working in aged care;
- Have the ability to support collaborative partnerships; and
- Have quarantined time to undertake the role.

DPRN perspectives on having allocated time for their role:

'...I had a designated day as a DPRN and I think that really you need it...You put on that "hat" for the DPRN role...and staff know [your in that role for the day]...I don't know how people can do it if they don't have quarantined time' (DPRN 1)

'You lose concentration [without allocated time]...It is totally difficult...not being able to ...keep that continuity (DPRN4)

Barriers

Studies have reported a number of barriers that may impede the success of a link nurse program. These barriers are highly relevant to the establishment of a resource nurse program and some of the most relevant barriers have been outlined here. A significant barrier to implementation, which has been well documented, is a lack of management support.^{17-18,22-23,26} Management support is crucial to the promotion of the role and its important in the facility as well as providing practical assistance such as allocated paid time for people who are taking on resource nurse or link nurse duties.^{17,22,27,30} Without these provisions, there is a risk that a resource nurse role might be seen as "another duty" with little reward, having insufficient allocated time and low status.^{27,31}

Staff shortages have also been well documented as a barrier to the staff member being able to effectively engage in a link nurse type role, as well as to being released to attend education sessions that could contribute to the development of their role.²³

The (lack of) confidence of link nurses to assume a teaching and mentoring role has also been documented as a barrier.¹⁷ Further, territorial issues between different staff members can be a barrier to the development of the resource nurse role.

DPRN about impact of managerial support:

I don't have a very supportive director of nursing and I think you need to have strong leadership from management at the top level to really promote the role I feel like I've... [had] low profile... I think if you had a supportive and strong manager who would really push the role I think that would be certainly a plus. (DPRN 1)

Box 2 contains a summary of the barriers likely to be encountered when setting up a DPRN program, and strategies to address each of these barriers are suggested.

Box 2: Summary of Barriers and Strategies

Barrier	Strategies
Lack of managerial support	<p>Managerial support is a precondition for program establishment.</p> <p>Have a set of expectations for management support of the program. (Outlined in Section 1 of this resource)</p> <p>Management involved in program design and delivery.</p>
Territorial issues with other professionals	<p>Clarity around role definition</p> <p>Focus on collaboration with other health professional as part of “the dementia/palliation agenda”</p>
Lack of time	Quarantined time—paid.
Lack of staff interest or confidence by DPRN	Staff member must have an interest in the area—and not be “volunteered” by management.
Inadequate preparation for role	Capacity building activities (including education and preliminary preparation) need to be built into the resource nurse program (see Section 2 of this resource).
Feeling “snowed under”	Set up a support group at the RACF, consider assistant/deputy DPRN.
Resistance by others or difficulty establishing collaborations with other sectors	<p>Promotion of benefits of the role, clarification of role and responsibilities.</p> <p>Development of relationships may necessitate a memorandum of understanding or some other type of agreement.</p>
Staff turnover/Transience through the role	<p>Set up an action group of RACF staff which will work with the DPRN.</p> <p>Consider appointing an assistant/deputy DPRN so that if the DPRN is unable to continue in the role, there will be someone who can take their place</p>

1c. DPRN recruitment

Recruitment of a staff member(s) for the DPRN role should be approached as a strategic activity within the organisation designed to enhance evidence-based practice. Recruitment of a DPRN should include the following activities:

- Raise awareness about the role (see Attachment 1).
- Provide staff with a position description (see Box 2) and any other supporting information about the DPRN role,
- Call for Expressions of Interest (EOI) from staff members who have a desire to take on this role (see Attachment 2 for example of an EOI).
- Undertake a formal selection process.

Depending on the number of staff that submit EOIs for the DPRN role, an action group which will support the DPRN could also be established. The enthusiasm of those staff members who are not successful in obtaining the DPRN position can be harnessed early by forming such a group. This is one potential strategy to address issues of staff transience through a resource nurse role (as highlighted in Box 3). Box 3 contains a DPRN position description, which RACFs could use as a guide to selecting a staff member to assume a resource nurse role.

Box 3: DPRN Position Description

Desired attributes of staff member filling the DPRN role:

- Qualification as a Registered Nurse (minimum 0.5 FTE)—the staff member needs to have a level of authority to implement and foster change at a unit level.
- Employment in participating RACF in current (permanent) position.
- Minimum of 12 months experience in residential aged care.
- Have a keen interest in dementia and palliative care.
- Ability to communicate and collaborate effectively with a range of aged care staff and other professionals.
- An interest in evidence-based practice.
- Ability to initiate and drive evidence-based activities in the facility (e.g., education programme)
- Enthusiasm and a desire to mentor other RACF staff
- Commitment and strong motivation to improve the provision of quality palliative care for people with dementia

Expectations for commitment to and engagement of the DPRN:

- Undertake role for one day per week (funded)
- Undergo an education programme focusing on palliative care, dementia, evidence based practice and change management
- Commit to engage in dementia/palliative care clinical-and education-focused activities

2. DPRN preparation

The DPRN role needs to be underpinned by education and resources to ensure that the nurse has the necessary knowledge and support to undertake the role. In terms of preparing staff members to take on a resource nurse role, capacity building activities are crucial and these should include:

- DPRN preparatory education program, and
- DPRN support networks.

DPRN preparatory education program

To prepare the DPRN for their role it will be necessary to provide them with education about the role itself, as well as the evidence around dementia, palliative care and principles of knowledge translation. For example in the *Dementia Care Dialogues* project the following areas were addressed in an introductory two-day education program for DPRNs:

- Demographics of an ageing population
- Dementia and increasing dependency in RACFs
- Introduction to palliative care and a palliative approach
- Applicability and benefits of a palliative approach for people with dementia in RACFs
- Communication strategies to facilitate a palliative approach to care for people with dementia in RACFs
- The Dementia–Palliative care Resource Nurse role
- Translation of evidence into practice
- Principles of change management

DPRN perspectives on the importance of education

I suppose, now that I've done the education and I've read a lot of literature, I know what I'm saying is right as well. So I've got the evidence I suppose, to say, 'Yes, I know this is right' (DPRN1)

I felt more confident [in the DPRN role] because I was more educated and I think that education is one of the major things (DPRN4)

3. Building support and engagement

3a. Action Groups

Establishing a group(s) of people to support the DPRN is crucial to ensure that they do not become isolated within their role. As previously highlighted, an action group of RACF staff is one strategy that can be used. An action group should comprise staff members who have an interest in dementia and palliative care (as discussed earlier, they could be people who applied for the DPRN role) and who will work with the DPRN and their colleagues to improve practice in this area.

Guidance on setting up Action Groups

There is no one correct way to establish an action group, however, there are some important questions and guiding principles that should be considered:

Who will comprise the action group?

A diversity of members will better equip the group to share a range of perspectives, identify problems for different stakeholder groups and share knowledge and skills to develop innovative solutions. There is no one ideal participant, however it is important that staff member have an interest in dementia, palliative care and evidence-based practice. For the group to be successful staff members will also need to be open and enthusiastic to exploring ways that their practices can be changed and improved.

How will members of the action group be recruited?

The establishment of an action group should ideally be led by the DPRN and involve liaison with facility management. High level buy-in from management is important for resourcing and support for the action group and reinforces the importance of DPRN-led initiatives.

While potential members can be accessed in a variety of different ways (e.g. on recommendation from management, participants in interest groups and other committees) it is essential that potential participants have a desire to be involved, rather than being “volunteered” by someone else. If staff feel like they have no choice but to be involved, it is less likely that they will be committed to the process. Invitation flyers/posters, highlights in newsletters, and public invitations in staff meetings are some suggested methods of alerting staff about the formation of an action group. Expressions of interest should be sought from staff (RNs, ENs, ECAs, and lifestyle and leisure officers) who wish to participate.

What do participants need to know prior to making a decision to be involved?

Working as part of an action group is an interactive process that at times can involve intense periods of work by group members. Participants need to be informed that they will be committing to work as part of a group over a sustained period of time. It is also important that participants know that they will be part of a knowledge translation process which relies on participation.

Preparation is critical:

Action group members will also need preparation to undertake their role. This preparation should be undertaken in conjunction with people who have expertise in knowledge translation and should familiarise the group members with the current evidence supporting the provision of a palliative approach for people with dementia and their family members; principles of knowledge translation; recognising barriers and enablers to knowledge translation; and knowledge translation strategies.

Additionally, there are a number of questions which the DPRN should consider with the action group members to plan how group meetings will occur and information will be communicated, such as:

- *What are the objectives of the group?*
- *How often will the group meet with the DPRN?*
- *How will group members communicate between meetings?*
- *How will the group members communicate with other staff in the facility?*

3b. Practice Development Network

In addition to setting up facility action groups, the establishment of a practice development network (PDN), which comprises professionals from aged care, palliative care and dementia specialist services is another important source of support for a DPRN and for DPRN-driven practice change within RACFs. Ideally, the PDN is a collaborative and self-driven group. PDN members are also likely to benefit from the DPRN and action group members' sharing of their hands-on experience in the facility.

A PDN would be responsible for:

- Collaborating with and supporting the DPRNs in their role.
- Assisting the DPRNs to access relevant evidence (including best practice guidelines (BPGs)) and experience.
- Provide expert clinical advice to support knowledge translation in the RACF.

Box 4 contains an example of the type of membership for a PDN.

Box 4: Examples of Practice Development Network membership

Representative(s) from specialist palliative care nurses

Representative(s) from a specialist geriatrics service

Advance planning nurse specialist

Representative from Dementia Behaviour Management Advisory Service

3c. Awareness raising

This final section of the Resource Kit provides some examples of awareness raising strategies that DPRNs and action groups can undertake to introduce the DPRN role to staff and share evidence-based information about issues relevant to providing palliative care for people with dementia:

- Develop a DPRN Expression of Interest Form – see *Attachment 1*.
- Develop an introductory letter or memo for staff about the DPPRN role – see *Attachment 2*.
- DPRN newsletter regularly distributed to RACF staff – see *Attachment 3*.
- Working with other staff as a mentor and role model
- Informally raising the profile of palliative care for people with dementia through conversations with colleagues
- Sharing evidence-based information with staff and other stakeholders (e.g. family members) related to dementia, palliative care or advance care planning – this could include sourcing and sharing relevant external resources, such as television and radio programmes, educational DVDs and information posters. See *Attachment 5* and *Attachment 6* for examples of information posters.
- Facilitating or conducting education for colleagues

Attachments

Attachment 1: DPRN expression of interest form

You are invited to consider applying to be the Dementia–Palliative Care Resource Nurse for your facility.

The selection criteria for DPRNs will include the following:

- Qualification as a Registered Nurse
- Employment in participating RACF in current (permanent) position.
- Minimum of 12 months experience in residential aged care.
- Have a keen interest in dementia and palliative care.
- Ability to communicate and collaborate effectively with a range of aged care staff and other professionals.
- An interest in evidence-based practice.
- Ability to initiate and drive evidence-based activities in the facility (e.g., education programme)
- Enthusiasm and a desire to mentor other RACF staff
- Commitment and strong motivation to improve the provision of quality palliative care for people with dementia

If you would like to be considered for this role, please provide your contact and other details below

Name: _____

Present role: _____

Qualifications: _____

Telephone: _____

Email: _____

Thank you for your interest and please return this form to [insert details of facility contact person here]

Attachment 2: Example of introductory staff memo

Jane Doe is our Dementia–Palliative care Resource Nurse

Jane is our newly appointed Dementia-Palliative Care Resource Nurse (DPRN).

Her role is to:

- Support staff to provide best practice in a palliative approach for people with dementia,
- Explore your educational needs,
- Share evidence-based information and resources with staff,
- Work with and support other staff to implement a palliative approach to care for people with dementia.

Jane will be working as the DPRN every Monday, but available for contact at other times.

Jane's contact details are XXXX



Attachment 3: Example DPRN Newsletter

Dementia Care Dialogues

Newsletter No. 1

3rd August 2011

- *Bonnie and Clyde* attended the Dementia-Palliative Care Resource Nurse Education Program held at the Menzies Centre, Hobart on Monday and Tuesday this week.
- The sessions covered the context and background to the project, Palliative Care, the Dementia-Palliative Care Resource Nurse (DPRN) role and collaborative research.
- DPRNs attended from two Residential Aged care Facilities (RACF) in Hobart and two in Melbourne.
- We had many opportunities to talk about our own workplace and start to talk about how we will involve everyone in moving the project forward.
- As you know, we have formed an Action Group and from here on you will be hearing much more from the group about the project and the changes we are going to implement.
- We really hope you will become as enthusiastic as we are, so please come and see us for more information, suggestions or if you have any problems you want to discuss.
- Watch this space for regular information sharing and updates on our progress.

Dementia: A Terminal Illness

Dementia is a life-limiting illness because brain changes result in impairment of many aspects of life.

In advanced dementia, the person is likely to:

- be unable to recognise people and objects,
- have difficulties communicating,
- be increasingly chair or bed-bound,
- be unable to dress, wash and feed themselves, and
- experience pain, sleep disturbances, incontinence, confusion and depression.



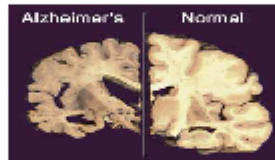
Eventually, they may lose the ability to swallow, and may develop repeated infections including pneumonia.

There is a slow progression through the stages of dementia to the person's death.

As dementia is a terminal illness, a palliative approach is an appropriate model of care.

Dementia

Not just a behavioural challenge, but a terminal illness.



Dementia is a progressive disease that affects the brain.

It presents in three stages:

1. Mild – work, social activity and memory is impaired.
2. Moderate – independent living becomes hazardous.
3. Advanced – cognitive and function are so impaired that the person requires continuous supervision and assistance in daily activities.

Dementia presents in a number of different forms, the most common of which are Alzheimer's and Vascular dementias.

The disease progression eventually leads to death, so dementia is considered a terminal illness. The average survival time for dementia is 4.5 years¹, but some people will die as soon as 6 months, or live as long as 20 years after diagnosis.



¹ AIHW (2007). Dementia in Australia: National data analysis and development. Canberra: AIHW.

References

- 1 Australian Institute of Health and Welfare. 2010. *Residential aged care in Australia 2008-09: A statistical overview*. Canberra: Australian Institute of Health and Welfare.
- 2 Australian Institute of Health and Welfare. 2011. *Pathways in Aged Care: program use after assessment*. Data linkage series no. 10. CSI 10. Canberra: AIHW.
- 3 Robinson, A., L. Venter, S. Andrews, K. Cubit, B. Menzies, L. Jongeling, M. Fassett & C. Mather. 2005. *Building Connections in Aged Care: Developing Support Structures for Student Nurses on Placement in Residential Care – Final Report*. Hobart: University of Tasmania.
- 4 Mitchell, S. L., J. M. Teno, D. K. Kiely, M. L. Shaffer, R. N. Jones, H. G. Prigerson, L. Volicer, J. L. Givens, and M. B. Hamel. 2009. "The Clinical Course of Advanced Dementia." *N Engl J Med* 361(16): 1529-38.
- 5 DoHA. 2006. *Guidelines for a Palliative Approach in Residential Aged Care - Enhanced Version*. edited by Department of Health and Ageing. Canberra, ACT: Department of Health and Ageing.
- 6 Hansen, E., C. Hughes, G. Routley & A. Robinson. 2008. "General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis", *Social Science & Medicine*, vol. 67, pp. 1776-1783.
- 7 Mitchell, S., D. Kiely, and M. Hamel. 2004. "Dying with Advanced Dementia in the Nursing Home." *Archives of Internal Medicine* 164(3): 321-26.
- 8 Sachs, G., J. Shega, and D. Cos-Hayley. 2004. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med*. 19(10):1057-1063.
- 9 Palliative Care Australia. 2005. *Palliative Care Quality Resource Guide: A Toolkit*. Deakin West: Palliative Care Australia.
- 10 Caron, C.D., J. Griffith, and M. Arcand. 2005. "Decision Making at the End of Life in Dementia: How Family Caregivers Perceive Their Interactions with Health Care Providers in Long-Term-Care Settings." *Journal of Applied Gerontology* 24(3): 231-47.
- 11 Addington-Hall, J. M., & I. Higginson. 2001. *Palliative care for non-cancer patients*. Oxford: Oxford University Press.
- 12 Hughes, J.C., K. Hedley , D. Harris. 2004. "The practice and philosophy of palliative care in dementia." *Nurs Res Care* 6(1): 27–30.
- 13 Shanley, C., and E. Whitmore. 2008. *Preparing for End-of-Life in Residential Aged Care : Research Project Report*. Sydney: Aged Care Research Unit, Liverpool Hospital.
- 14 Chang, E., J. Daly, A. Johnson, K. Harrison, S. Easterbrook, J. Bidewell, H. Stewart, M. Noel, and K. Hancock. 2009. "Challenges for Professional Care of Advanced Dementia." *Int J Nurs Pract* 15(1): 41-7.
- 15 Allen, S., M. O'Connor, Y. Chapman, and K. Francis. 2008. "The Implications of Policy on Delivering a Palliative Approach in Residential Aged Care: Rhetoric or Reality?" *Contemp Nurse* 29(2): 174-83.

- 16 Maddocks, I. 1999. *Palliative Care Nurse Practitioners in Aged Care Facilities : Report to the Department of Human Services*. Daw Park, SA: International Institute of Hospice Studies, Flinders University of South Australia.
- 17 Hasson, F., W. G. Kernohan, M. Waldron, E. Whittaker, and D. McLaughlin. 2008. "The Palliative Care Link Nurse Role in Nursing Homes: Barriers and Facilitators." *J Adv Nurs* 64(3): 233-42.
- 18 Froggatt, K. A., and L. Hoult. 2002. "Developing Palliative Care Practice in Nursing and Residential Care Homes: The Role of the Clinical Nurse Specialist." *J Clin Nurs* 11(6): 802-8.
- 19 Chang, E., S. Easterbrook, K. Hancock, A. Johnson & P. Davidson. 2010. "Evaluation of an Information Booklet for Caregivers of People with Dementia: An Australian Perspective." *Nursing & Health Sciences* 12(1): 45-51
- 20 Phillips, J. L., P. M. Davidson, D. Jackson, and L. J. Kristjanson. 2008. "Multi-Faceted Palliative Care Intervention: Aged Care Nurses' and Care Assistants' Perceptions and Experiences." *J Adv Nurs* 62(2): 216-27.
- 21 Roberts, C., and D. Casey. 2004. "An Infection Control Link Nurse Network in the Care Home Setting." *Br J Nurs* 13(3): 166-70.
- 22 Byron, S., D. Moriarty, and A. O'Hara. 2007. "Macmillan Nurse Facilitators: Establishing a Palliative Resource Nurse Network in Primary Care." *Int J Palliat Nurs* 13, no. 9 (): 438-44.
- 23 Cotterell, P., C. Lynch, and D. Peters. "Bridging the Gap: Can a Link Nurse Initiative Influence Palliative Care in an Acute Hospital?" *Int J Palliat Nurs* 13(3): 102-8.
- 24 Waldron, M., F. Hasson, W. G. Kernohan, E. Whittaker, and D. McLaughlin. 2008. "Evaluating Education in Palliative Care with Link Nurses in Nursing Homes." *Br J Nurs* 17(17): 1078-83.
- 25 Charalambous L. 1995 . "Development of the link-nurse role in clinical settings." *Nursing Times* 91(11): 36-37
- 26 Heals, D. 2008. "Development and Implementation of a Palliative Care Link-Nurse Programme in Care Homes." *Int J Palliat Nurs* 14(12): 604-9.
- 27 Friedewald, M. 2009 . "Link nurse programs: worth the effort?" *Healthcare Infection* 14: 39-40.
- 28 Whittaker, E., W.G. Kernohan, F. Hasson, V. Howard, D. McLaughlin. 2006 . "The palliative care education needs of nursing home staff." *Nurse Education Today* 26: 501-510.
- 29 Whittaker, E., W.G. Kernohan, F. Hasson, V. Howard, D. McLaughlin. 2007. "Palliative care in nursing homes: exploring care assistants' knowledge." *International Journal of Older People Nursing* 2(1): 36-44.
- 30 Seymour J.E., D. Clark, P. Bath, N. Beech, J. Corner, H.R. Douglas, D. Halliday, J. Haviland, R. Marples, C. Normand, J. Skilbeck, T. Webb. 2002 . "Clinical nurse specialists in palliative care. Part 3. Issues for the Macmillan Nurse role." *Palliative Medicine* 16(4): 386-394.
- 31 Martin B & King D. 2008. *Who Cares for Older Australians? A Picture of the Residential and Community based Aged Care Workforce 2007*. Adelaide: National Institute of Labour Studies, Flinders University.