

# Rural Palliative Care Resource Kit



**Adelaide Hills**  
Division of General Practice Inc.

## Establishing a Palliative Care Link Nurse Group

*Author*

**Deb Rawlings**  
**Adelaide Hills Division of General Practice**  
**South Australia**

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# Introduction

This document examines the benefits and barriers to:

- establishing palliative care link nurse groups
- the role of the facilitator
- setting up a group
- examples of activities that have been undertaken
- a review and development, along with some of the experiences from within the Rural Palliative Care Program (RPCP).

The information contained within is aimed at assisting other divisions looking to establish programs and specifically palliative care link nurses. This document details lessons learned from within the literature and from practical experience.

## *Box One - Important points*

- Having a link nurse can mean an increase in the quality of care.
- Link nurse models enable a greater number of people access to palliative care expertise.
- Lack of managerial support, the time and cost involved and distances to travel can mean limited attendance at meetings.
- Link nurses need to be recognised as such, with time to engage in additional and sometimes complex duties.
- Link Nurses need to have specific interest in Palliative Care, and should not be 'volunteered'.
- Link nurses need to be equipped with skills and education, and supported in managing change.
- There is a risk that link nurse are regarded as a substitute for the Specialist Nurse, or that they will de-skill colleagues.

## What is a link nurse or link nurse system?

A link nurse, for the purposes here, can be described as a nurse with an interest in palliative care, who is a resource person, forming a direct link to the palliative care specialist nurses and to each other. The role involves attendance at meetings where ideas and new developments can be discussed, with information then disseminated from the specialist nurse back to the clinical area, providing formal two-way communication<sup>1,2,3</sup>.

The concept of Link Nurses is familiar within nursing, traditionally having been used within acute areas such as infection control, stoma care, diabetes and wound care<sup>3</sup>. However, little can be found within the literature on link nurse schemes. Within palliative care even less has been reported, although anecdotally it is known that they are in place in many areas<sup>1,3</sup>.

There is no consensus on the most effective model of link nurse system, with many being set up to address specific issues or problems such as sharing work across private-public sector boundaries, or as a pilot project to look at the role of a nurse practitioner<sup>2,4,5,6</sup>. In most instances, in one way or another, these groups have been set up as part of the ongoing way a nurse specialist can address the scope of the role.

## Benefits

It is unrealistic for many reasons including workforce issues, for Palliative Care Specialist Nurses to be involved with every dying patient<sup>2</sup>. Development of link nurse programs can be regarded as a means to develop practice, and to encourage staff to take responsibility for aspects of palliative care themselves<sup>7</sup>.

Link nurse groups could lead to an increase or enhancement in the quality of care offered to patients. Link nurses are trained in connected to best practice clinical areas at the grass-roots level, this is a valuable way to promote clinical effectiveness<sup>1,3,4</sup>. Link Nurses can be a bridge between theory and practice<sup>1</sup>. They can help to improve communication between specialist teams and managers, and are able to introduce new practices and enhance patient care<sup>2,8</sup>. The link nurse has the potential to reach staff as they usually work in the clinical area as an ongoing resource, which can be especially helpful for new staff<sup>3,4</sup>.

## Aged Care

Much of the work that has been reported in the literature, has been undertaken in aged care, with specialist nurses (Clinical Nurse Consultants or similar) liaising with Residential Aged Care Facilities (RACF) to optimise the care of the dying in these settings. This is the way in which the Adelaide Hills Division of General Practice (AHDGP) group has evolved, in response to a local funding anomaly. A PowerPoint presentation on RACF is available on the Palliative Care Australia website, and can be accessed here.

[http://www.pallcare.asn.au/pdf/presentation\\_pdf/P008.pdf](http://www.pallcare.asn.au/pdf/presentation_pdf/P008.pdf)

There is little within the Aged Care Standards that specifies what should be in place in a RACF for residents who are dying (see links below). There is, perhaps the potential in the future, to link the 'Standards for Aged Care Facilities' with the 'Standards for Providing Quality Palliative Care for all Australians' which would help to address this, naturally detailed discussions would need to occur with the relevant stakeholders.

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-standard-facility-sacfindx.htm>

<http://www.accreditation.org.au/AccreditationStandards>

The Resident Classification Scale (RCS) system of funding used in Australian aged care facilities meanwhile, provides little or no financial support when complex symptoms occur at the end of life, nor for the emotional support required by families during a terminal phase of a loved one<sup>6</sup>. Anecdotally care managers find it difficult to accommodate the way in which residents should

ideally be cared for, such as one-on-one care for those who are close to dying, as extra care or time spent has cost implications.

Link Nurse systems could arguably be promoted as a way of facilitating ongoing 'best practice care' at little or no extra cost to the organisation on a daily basis. There are opportunities to work collaboratively across organisations and across geographical boundaries, to adopt evidence-based guidelines such as Guidelines for a palliative approach in RACF, (see box two) and clinical pathways. This can only improve outcomes, which is in itself a cost-benefit approach for the long-term.

Within the Rural Palliative Care Program (RPCP), some projects have worked in conjunction with the Aged Care panel initiatives (<http://www.adgp.com.au/site/index.cfm?display=2343>) run via the AGPN Network to also co-ordinate and promote collaborative pathways of care.

### **Box Two: Guidelines for a Palliative Approach in Residential Aged Care Facilities**

Excerpts from '**Guidelines for a Palliative Approach in Residential Aged Care**' (Enhanced version, May 2006) APRAC Project. Commonwealth of Australia

Australian Standards for Aged Care and Standards for Palliative Care exist, but do not fully address the unique and complex issues associated with providing a palliative approach in residential aged care facilities.

The guidelines can be used to prompt creative, locally relevant care solutions, and identify strengths and weaknesses of the current approach, providing mechanisms for change

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-pubs-workf-guide.htm>

## **Enablers**

Ideally a link nurse should be a keen, enthusiastic, motivated volunteer, who has a particular interest in the specialty, and a degree of knowledge, skills and professional credibility to develop the role<sup>1,3</sup>. The commitment of Link Nurses is often underestimated, as many have a real passion for palliative care and for their residents, which drives their involvement and the way in which they then take information and initiatives back to the workplace. Considerable numbers of link nurses fund their own attendance, and also attend in their own time thus demonstrating that their desire to participate is stronger than their organisations' ability to support them<sup>5,6,9</sup>.

Early involvement of key influencers or enablers, has been identified as having a major impact on the success of programs, with these so-called 'champions' an important factor in their success<sup>2,8</sup>. The link nurses themselves are often the champions, but it is only with the support of management and staff within their organisation that they can truly develop the role to its full potential. Some of the link nurses will be the care managers of smaller organisations. However others will be Registered or Enrolled Nurses with little or no influence or support to 'champion' the process.

- Passion
- Support
- Coordination
- Champions
- Motivation
- Knowledge/skills

## Barriers

The lack of managerial support to get to meetings has been well documented as a barrier to the implementation of link nurse groups<sup>2,3,5,7,8,9</sup>. These meetings can be seen as a low priority when compared with the resources required in daily clinical work<sup>8</sup>.

Staff shortages can mean that there is difficulty in releasing qualified staff to attend study days or meetings in work time<sup>5,7</sup>. Managers need to account for the hours spent away from the clinical care, such as the cost of replacing staff<sup>1,2,4</sup>. Certainly in low care facilities it is nearly impossible for the link nurse to leave the workplace if they are the only RN on duty<sup>6</sup>. Managers do often acknowledge and recognise the importance of schemes such as these, but the costs of supporting staff are often prohibitive, especially in smaller organisations. The fact that aged care facilities are businesses can never be overlooked<sup>10</sup>.

Poor attendance at meetings is not only as a result of the earlier identified managerial issues, but can also be explained by geographical and travel difficulties, which is especially true in rural areas, where distances to travel only increases the time spent away from the workplace<sup>5</sup>.

One difficulty from within the workplace, is that link nurses are not being given sufficient time to carry out their link nurse work as well as their existing duties, sometimes a managerial coordination issue but often due to a lack of recognition and support from colleagues<sup>4,8</sup>.

In some instances, managers agree to representation on these groups and 'volunteer' staff to become a member. Coercion is not ideal, as this then affects that persons' motivation to engage in the program<sup>8</sup>. Certainly a personal interest in palliative care is an important factor<sup>2</sup>.

Sometimes link nurses will not stay with the group, as people leave, move to other areas or are promoted. This means that any new person needs to integrate into the established group, and some geographical regions with a high turnover of staff will possibly find difficulties in maintaining these groups.

- Cost imperatives
- Requires coordination
- Support from management and peers
- Can be seen as 'another' duty
- Travel requirements etc

## The Role of the Facilitator

Much of the published work on link nurse systems has described the situation where a nurse specialist or a specialist team develop the group<sup>4</sup>. The role of specialist nurses is diverse, and usually encompasses much more than just the clinical role, although this will vary. There is often not the capacity to undertake extra work, for example within care homes, as it has to be balanced with the demands of the rest of the caseload<sup>7</sup>.

The link nurse group meetings are then often facilitated by these nurse specialists, providing educative and consultative support and empowerment for the nurses in the program<sup>8</sup>. They are able to help practitioners to offer good generic palliative care to all residents, and educate staff to know when to call in specialists, identifying referral and advice pathways<sup>7</sup>. The link nurse relies on the nurse specialist to provide accurate, relevant and up-to-date information about best practice, and to keep motivation and interest<sup>1,9</sup>.

It is important to recognise the risk that the link nurse is regarded as a substitute for the specialist nurse, filling the gaps, becoming a point of referral and eventually eroding the specialist role<sup>1</sup>. Alternatively, there is the concern that the Link nurse will de-skill colleagues however experience does seem to show that these nurses tend not to undermine others, or take away their responsibility to inform and update themselves<sup>3,4</sup>. Rather, the link nurse role has tended to be more about dissemination of information, with the emphasis on informing, motivating and empowering colleagues.

Role delineation is vital and should be emphasised not only within the group but with managers and facilities. Providing written information for everyone on what a link nurse is, **and** what they can realistically achieve will help with clarification<sup>3,7</sup>. There are diverse perceptions of the link nurse role, which has implications for the role of co-ordinators and participants<sup>7</sup>.

Dissemination of relevant information back to the workplace is important; however attendance at meetings doesn't necessarily mean that this happens<sup>2</sup>. It therefore needs to be emphasised that this is a main outcome of the role. At the same time the Specialist Nurse depends on the link nurse to raise questions relating to the care needs of special patients<sup>1</sup>. Communication in all areas, in all directions, is vital.

It is also recognised that the facilitator role places an extra burden on the specialist nurse, in preparing for the meetings, planning educational sessions and delivering training<sup>3,5</sup>. Administration costs also need to be factored in, such as reminders about meetings, organising documentation, photocopying and so on<sup>3,4</sup>. Sometimes this, along with a lack of resources is a factor that affects the ability of nurse specialists to undertake this work<sup>5</sup>.

## Setting up a Group

Establishing a link nurse group isn't as simple as getting together a group of like-minded individuals<sup>5</sup>. Writing to managers within the relevant organisations, with group objectives and an invitation for each organisation to nominate someone to be a link nurse can help garner the support of managers<sup>6</sup>. Nurse managers are ideally placed to disseminate information about link nurse programs, identifying potential participants and providing the opportunity and support for interested staff to participate<sup>8</sup>. Written contracts have been used in some areas in the form of a learning contract also signed by the unit manager and nurse specialist helping to formalise arrangements<sup>4,8</sup>.

It is important to clarify early on is who will be invited to the group? Sometimes multidisciplinary team members are included, such as community aged care package and volunteer co-ordinators<sup>2</sup>. It is also important to consider how long will meetings be held for? How often will they be held, and where will they be held? Monthly meetings have been quite popular, but groups have been brought together as infrequently as twice a year<sup>6</sup>. Sometimes it is easier to run a whole study day, as this facilitates easier release from the ward, however all this often means is that the nurses undertake this work in their own time<sup>2</sup>.

Education and training for link nurses has been highlighted as being important, and this should ideally commence when the group is formed, ensuring that all link nurses have the same knowledge foundation.<sup>3,5</sup> An orientation or training day (or days) is perhaps the preferred option, with a 3 day link nurse training course being implemented in a pilot project in SA<sup>6</sup>.

Link nurses may also need further education, teaching and dissemination skills to be prepared for their role<sup>1,2,4</sup>. They can be involved in activities that include encouraging colleagues to practice up-to-date research-based practice, educating other nurses, passing on information, improving practice and monitoring and auditing care<sup>1,4</sup>.

Link nurses can also be a catalyst for change, a role that they need to be aware of<sup>4</sup>. It should be recognised early, that there is often difficulty in promoting change in institutional settings<sup>8,10</sup>. A session on 'managing change' for the link nurse can offer practical skills to utilise in the workplace, which also enables them to challenge attitudes and beliefs<sup>6</sup>. Certainly, poorly managed change can lead to limited effectiveness of the change initiatives<sup>11</sup>.

## Group activities

There are a range of activities that can be undertaken within Link Nurse Groups. Many groups are only able to facilitate the development of resource folders or displays for use within organisations, while other groups offer professional support and a chance to discuss case histories<sup>2,4,9</sup>. Most groups organise visiting speakers, presentations and lectures<sup>2,3,4</sup>. It is important to keep the program interesting and stimulating, to meet the needs of the group and help motivate members<sup>9</sup>.

Often a combination of activities will best suit what can be a short time-frame for meetings. Including opportunities for reflection on practice and sharing of experiences, as well as formal education<sup>2,6</sup>. This format can create an environment in which participants can learn from each other with the benefits of networking between members<sup>2,5</sup>.

What is often also valued is the opportunity to enable the link nurse to spend clinical time with the specialist palliative care nurse<sup>29</sup>. Within Australia the Program of Experience in the Palliative Approach (PEPA) Program (see box three) provides a more comprehensive version of this, and has been extensively promoted by RPCP projects. It is nice to be also able to offer incentives for Link Nurses, and these have included things like badges, educational programs, places at national conferences, resource folders for the clinical area and free lunch<sup>2</sup>.

### *Box Three: PEPA Program*

The PEPA Program is the Program of Experience in the Palliative Approach. It is an Australian Government Department of Health and Ageing initiative under the umbrella of the National Palliative Care Program. This program provides an opportunity to learn from experienced specialist staff to enhance skills, knowledge and experience in the palliative approach. <http://www.pepaeducation.com/>

PEPA is being implemented in all Australian states and territories.

## Review and development

Every group needs to be reviewed for ongoing effectiveness and link nurse groups are no exception. When reviews have been undertaken elsewhere, the results have been a positive reinforcement of the aims and objectives of the group (see box four).

Feedback can provide a valuable opportunity to review the educational content, identifying training needs, structure the program, and construct a program for future meetings<sup>3,9</sup>. Reviews can also demonstrate the value of such groups, showing for example, that nurses have been motivated and keen to learn more, or that they have increased knowledge, confidence and sense of empowerment<sup>2,9</sup>. Auditing attendance at meetings can also be used to assess overall attendance, thereby demonstrating which organisations may need more input and encouragement<sup>3</sup>.

Suggestions have been made to map the impact that the program has on the development of nurses over time, and it has also been proposed that this role could be validated for ongoing career development<sup>1,2</sup>. As a support to the Nurse Specialist, perhaps their salary or grade should reflect this, although realistically this is unlikely in current financial climates<sup>4</sup>.

## Conclusion

The role of link nurses is a means of improving the delivery of evidence-based care between particular settings<sup>5</sup>. Link nurse models enable a greater number of residents access to palliative care expertise, as well as providing an opportunity for staff from RACF to share knowledge on not only palliative care issues and issues common to aged care<sup>6</sup>. The end result has meant that staff in RACF are better able to support residents, families and each other in dealing with terminal care issues<sup>6</sup>.

**Box Four: Comments from AHDGP Link Nurse Survey**

**Adelaide Hills Palliative Care Link Nurse Survey**

Questionnaires were administered in September 2006 towards the end of the rural palliative care project. Some of the comments from the nurses are shown here.

When asked **whether they felt the link nurse group had been a worthwhile experience** Comments included:

*"It has helped me become aware of the needs for palliative care information and practice to be promoted in our facility"*

*"Sharing ideas, networking, being part of the clinical pathways, bereavement pack etc... has been a really satisfying experience"*

*"Increase my awareness of the Palliative Approach in residential aged care. Improved my knowledge of the Standards of Palliative Care. Gained ideas from Link group (and support)"*

*"Very worthwhile – update information – exchange with colleagues"*

When asked **what they had implemented or changed in their workplace** as a result of being a part of the group. Comments included:

*"Implementing a new care plan....developed from the clinical pathways"*

*"Use of graseby pump/ information increased confidence"*

*"Forward planning medication orders etc..."*

*"Palliative Care folder....regular education sessions prior to staff meetings"*

*"Implemented bereavement packs, clinical pathways...syringe driver recording and documentation"*

*"Palliative care plan formulated and currently in draft to trial"*

*"Introduction of clinical pathways, development of a new assessment tool for palliative patients"*

## Personal reflections of Rural Palliative Care Program (RPCP) experiences with Link Nurse Groups

The following testimonials are from those involved with the RPCP, and give differing views and experiences on these groups

### ***Adelaide Hills Division General Practice (AHDGP) Link Nurse Group***

The Link Nurse Group was established at the beginning of 2005. There are certain funding issues in the Adelaide Hills in regards to the palliative care service. This has resulted in the palliative care nurses being unable to visit residents in Aged Care Facilities unless they charge for their services. This of course means that referrals are generally low, except for telephone support and crisis management.

A group of nurses were brought together who had a demonstrated interest in palliative care, forming a direct link to the Palliative Care Specialist Nurses. They represent all 5 local hospitals and 9 out of 10 of the local residential aged care facilities (a local hostel did not participate).

Each representative had varying experience and education in Palliative care which was addressed on an individual basis. Each was offered clinical placements with the Palliative Care CNC, were encouraged to apply for PEPA, were offered paid study days, given free lunch at meetings and were able to access the DGP Palliative Care CPDs at no charge.

The group was formed following visits to the Director of Nursing of each organisation to elicit support for this venture. They were supportive in theory but this did not necessarily translate into helping the nurses to get away from work or being given paid time to attend meetings. Some of the nurses came along in their own time – something that continued for quite a while. despite letters being written, again eliciting formal support for the initiative.

Lunchtime meetings every month then became a day away every two months. It is held in rotating venues across the Hills, enabling the nurses to visit each others' workplace. This is easier to organise. If it were not for the interest, passion and commitment of the nurses, this group would never have continued to become the proactive cohesive group that they are now.

Guest speakers have been invited, and the group have worked on many initiatives over the 2 years they were part of the rural palliative care program. They continue to meet under the mentorship of the Palliative Care CNC, working towards improved palliative care outcomes in the Adelaide Hills.

**Deb Rawlings**

**Palliative Care Project Manager, Adelaide Hills DGP**

## Reflections from the Southern Queensland Rural Division General Practice (SQRDGP) Link Nurse Group

### *Reflections from two Link Nurses on being part of the Adelaide Hills Link Nurse Group*

"When we were invited to attend the first meeting of the Adelaide Hills Palliative Care Link Nurse Group, as representatives from Mount Pleasant Hospital, in Jan 2005 we weren't entirely sure what to expect. We both had an interest in Palliative Care, although no formal Palliative nursing training and it seemed like a good idea at the time....

We expected that the group would share information about best practice within Palliative Care and perhaps come away with some ideas that we could take back to our health unit which would improve the quality of the Palliative Care that we were currently delivering- little did we know just how this would evolve.

As our involvement with the Link Nurse Group grew, so did the enthusiasm for 'doing this so much better'. With support from the group we successfully applied for a grant from the Department of Health & Ageing which allowed us to develop a dedicated Palliative Care suite, Reflection room & purchase equipment for home use. We identified gaps not only in our personal knowledge, but also in the systems and processes within our health unit and which were already in place to provide good Palliative care for our patients and residents.

In order to address these gaps we have researched and developed a number of Palliative Care specific tools such as assessment forms, care plans, family charts, and have also adopted the Palliative Care Clinical Pathways, and Bereavement Resource Folders, which were developed within the Link Nurse Group, for use within our health unit.

The introduction of these tools has created a wider awareness and interest in palliative care among nursing, care & medical staff. This has had a 'ripple' effect which has resulted in a number of our aged care residents now having Advance Directives or a Good Palliative Care Plan in place, the implementation of a Bereavement Support Programme, education for all staff around Palliative Care issues and the commencement of the National Palliative Care Standards Implementation Project which will support & expand the care we currently give to Palliative patients and their families.

During this journey the Link Nurse Group has provided us with the knowledge, support & confidence which has assisted us in achieving such good outcomes. Many thanks to Deb Rawlings & the other members of the group".

**Jean Vredenburg**  
Clinical Nurse  
Mount Pleasant Hospital

**Aylene Mueller**  
Enrolled Nurse  
Mount Pleasant Hospital

### **South Burnett Link Nurse Group**

The Link Nurse Group in the South Burnett had one essential difference in the RPCP Program in that they were established from a Primary Care focus without access to local a Specialty Palliative Care Service. The local Program called itself the Rural Palliative and Advanced Care Program (known as RPAC) to try to extend the concept of caring for all patients that required an approach based on care not cure. The majority of the 28 doctors across the district managed their palliative patients in hospital or in their homes. As an initiative of the RPAC Program, case conferencing was developed that allowed for a team approach and a more holistic review of patient Carers and family needs. Many of the nurses that attended Case Conferences became Link Nurses.

RPAC engaged a group of twenty-five (25) Nurses from across the region. Nurses were selected in relation to positions within the community and level of dedication to providing quality palliative care. Their Senior Line Managers were approached in each organization and an agreement in principle was reached as to the role the nurses would play. All sectors were approached i.e. RACF's hospitals, domiciliary & community services and General Practices.

It was identified, through data collected for the University of Wollongong Evaluation, that the RPAC Program stakeholders had less on-the-job training (overall 52%, compared with 45% for RPAC) and a greater proportion of service providers with no training (19% compared with overall 10.7%). Capacity Building became a high priority and the Link Nurse Group proved an excellent forum for achieving this aim.

An intensive education program was planned and implemented over a six month period (refer to Additional Tools). The Brisbane South Palliative Care Collaborative (BSPCC) was engaged to conduct three intensive workshops to give the nurses a strong foundation in Palliative Care with particular emphasis on Opioid Conversions and Symptom Management (identified at Link Nurse inaugural meeting). The education days were aligned with the fly-in fly-out visiting Palliative Care Specialist - Dr Liz Reymond Director of BSPCC. The advantages include allocating a single day allowed for two trainers; reduced travel time - from a 5 hour round trip to a 40 minute flight each way; and removed the need for overnight accommodation which offset the cost of flights.

This alliance also served the purpose of creating professional links and supports for the nurses practicing in isolation in a rural setting. The relationship building with the Palliative Nurse Specialists expanded into ongoing support on completion of the training as the Link Nurses were confident to call for advice or support in their daily practice.

For geographical and logistical reasons the Link Nurses formed two subgroups and met on different days. For cost and efficiency, Link Nurse education was held at a central point at a venue and time to suit the majority of the Group. The Link Nurses decided on monthly breakfast meetings before the Case Conferences, attended in their own time. At this meeting participants shared any findings i.e. new articles, conferences; debriefed (formally with a Social Worker; every 3 months); discussed local issues and built relationships where previously there had been none. Due to the success of the Link Nurse Group, the sustainability of the Case Conferencing was viable and has continued past the end of the Program.

Positive outcomes included the validation and up-skilling of nursing practice and relationship building within the local nursing community. A surprising outcome was a marked increased in knowledge of services and resources available for stakeholders and families. The dedication and selflessness of this group of Nurses (and their organisations) is acknowledged.

**Linda Rudorfer, RPAC Coordinator (SQRDGP)**

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