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Aged Care Reform Series - Palliative care

The National Aged Care Alliance (the Alliance) developed this paper to provide additional advice to Government, through The Hon Mark Butler, MP Minister for Mental Health and Ageing, as it considers the proposed aged care reforms from the Productivity Commission's Caring for Older Australians report which was released in August 2011. Palliative Care is one in a series of six papers available on the Alliance website (www.naca.asn.au), other papers in the series include: Assessment and entitlement (including the Gateway), Financing aged care in Australia, Quality of care, Wellness and Workforce.

Introduction

All Australians should be able to expect to die with dignity and have as much control as possible over the circumstances of their death including being with the people they wish to be present and, whenever possible, in the place of their choice.

Palliative care is markedly different from the mainstream medical approach that focuses on curing illness and protecting life as an over-riding priority.

Government and the sector has developed the National Palliative Care Strategy and there are guidelines for a palliative approach in both residential and community aged care settings. However, there are still significant issues and challenges that need to be addressed in the provision of these services to older Australians, including in aged care.

What is good quality palliative care?

The World Health Organizations definition of palliative care highlights some of the elements of good palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

The Alliance supports this definition and the elements of palliative care it describes. In addition though the Alliance points out that the delivery of quality palliative care is most likely to be realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people[1].

Palliative care and end of life care

It is important to distinguish between palliative care, as described above and which may be provided over the course of a life threatening illness (including chronic or degenerative conditions) and end of life care which refers to the care provided in the last weeks/days of life. End of life care is only one stage of quality palliative care provision and is often when people are at most risk of being inappropriately referred to hospital.

Palliative care and people with dementia

Dementia care is palliative care. Dementia care as palliative care requires a different approach than palliative care for conditions such as cancer as the *process* will take place over a longer period of time, involves early engagement in advance care planning, and requires more flexibility than palliative care approaches to other diseases. This is because unlike cancer, where a person at the end of their life is likely to be similar in personality and cognitive ability to the person first diagnosed, the course and prognosis of dementia means that most people with the disease will be subject to significant changes in cognition, functional abilities, and possibly behaviour, emotions and personality. This means that the palliative care process evolves over time, and involves a shift in the locus of control and decision making from a collaboration involving the person with dementia, their carers and health professionals in the early stages, to carers and health professionals only later on.

Declining cognition also means that a person dying with dementia is unlikely to have the capacity (legal or functional) to make decisions and communicate their preferences regarding care. This means that any such decisions must be made much earlier in the course of dementia than for other diseases, or alternatively, must be made by proxies on behalf of the dying person. Dementia is difficult to diagnose in the early stages, and while dementia inevitably leads to death, the prognosis, once diagnosed, is difficult to determine. Unlike other terminal illnesses where the course and prognosis might be given with relative certainty at the time of diagnosis, the unpredictable course of dementia (in terms of both time and rate of decline) means that the palliative care process will require greater flexibility to adapt to new circumstances as the condition progresses.

Barriers to the provision of quality palliative care

Although aged care services are provided towards the end of life, and death and dying are no strangers to aged care, the provision of quality palliative care in residential and community care settings (particularly for the majority of people who have dementia - 53% with a diagnosis in RACF; AIHW 2011), is the exception rather than the norm.

Conversations about dying are generally ad-hoc, and remain largely taboo. Symptoms such as pain and dysphasia are often managed poorly; and end-of-life processes such as respiratory failure, dehydration and anorexia are too often treated as medical emergencies that prompt hospitalisation,

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[1] Palliative Care Australia

rather than as normal components of a terminal process that can generally be managed appropriately by palliative care teams in situ or by staff with education and clinical confidence in providing end of life care.

Any discussion of barriers and disincentives to the provision of quality palliative care must acknowledge the widely variable financial arrangements around Australia for these services. The different approaches to funding and delivery of palliative care create quite different outcomes for individuals depending on where they live. In WA, for example the state government provides significant funding for home palliative care through Silver Chain and this service is often quoted as best practice with 60% of admitted clients dying at home. WA also has a lower rate of people dying in hospital.

There are different barriers and disincentives for the provision of quality palliative care in residential and community care which are outlined below.

Residential care barriers and disincentives:

- Inability to meet ACFI palliative care funding requirements for care to be under the Directive of a CNC/CNS in pain or palliative care (with 5 years experience) or medical practitioner AND include a Pain assessment. Lack of access to these professionals, and the absences of pain for people with non malignant diseases (such as end stage respiratory disease) make claiming for palliative care difficult.
- No funding for the provision of bereavement services, including psychological services for families of residents pre/post death.
- Residential care standards embed an end of life care focus. Proposals to add a three month time frame for this care will further entrench this approach.
- Lack of systems and processes to assist care staff and case managers to make appropriate decisions at time of medical crisis (particularly agency nurses, or care staff who do not know the resident and their particular situation).
- Limited/no access to the latest equipment because of funding levels and restricted grant opportunities available to residential age care.
- Lack of appropriate funding for the delivery of palliative care, including for appropriate equipment. Current funding under the ACFI for palliative care is only around one third of the amount that specialist palliative care services receive per individual and is only provided for end of life care.
- Inadequate access to specialist palliative care consultancy services to augment care provision for people with complex needs.

Community care barriers and disincentives:

- Community aged care funding does not include any explicit provision for palliative care and there is an explicit assumption that this is provided through the health system.
- Ambiguity of HACC policy guidelines around provision of, and access to specialist, palliative care services. There is tension between the programs with people needing palliative care sometimes being denied access to HACC services.
- In some regions people who are receiving palliative care are denied access to packaged care and the reverse can also occur with people who are receiving packaged care being denied access to palliative care services.

There are some barriers and disincentives which affect the provision of palliative care in a residential or community setting including:

- Limited access to general practitioners (themselves sometimes not trained in palliative care), to palliative care specialists (under agreed and consistent referral and access criteria), to nurses (who can administer opioids) and other health professionals (such as allied health professionals) to ensure multi-disciplinary care is provided. This is equally true in the community and in residential care.
- Limited access (sometimes) to PBS-subsidised palliative medicines. The bigger issue can be access to non-PBS listed drugs that are available in hospital because the State governments fund them. This provides a significant disincentive to returning to the community.
- Lack of education and training of both new and existing (up skilling) staff including in clinical care requirements and in case management/co-ordination processes (e.g. case conferencing, use of advanced care directives etc).
- Limited adoption of advance care planning – often not developed in a timely way and in some cases, not stored or recorded in ways that will allow them to be effective when needed (they may, for example, be stored in resident/client files that are not transferred to hospital if an ambulance is called).
- Limited knowledge of, and no universal access to, available specialist and community palliative care services and resources.

These barriers are exacerbated for people with dementia, where pervasive stigma and misunderstanding of the condition (on the part of both aged care providers and family carers), poor recognition of symptoms, and communication barriers often result in missed opportunities for quality palliative care, and as a result there are many acute and unnecessary hospitalisations.

Not all of the issues facing the provision of good quality palliative care for older people lie in specific aged care services. More broadly the specialist palliative care services are often time limited (in QLD for example there is a three month limit). This criterion is difficult to meet for older clients with non malignant disease where prognosis is much less certain than for clients with a defined malignancy.

One other aspect to consider here is why aged care services do not generally seek to become specialist palliative care providers either in the community (as Silver Chain has done in WA) or in residential care given their infrastructure suitability for the provision of hospice care. Access to state government funding can be limited and the entry of new players creates further competition for limited resources. However as the nature of residential care service provision changes to more short term interventions with people who are frailer and have higher needs, eligibility for state funding and federal responsibility for older people will need to be actively considered to ensure that quality palliative care is available for this target group.

The role of aged care services in providing palliative care

Palliative care is core business for residential aged care facilities and this will increasingly be the case for community care as people remain living at home for longer. Length of stay in residential aged care is decreasing. The percentage of separations by death in residential aged care facilities in Australia has increased steadily from 70% in 1993 to 87.8% in 2008. Of these residents, 16.5% had stayed for less than three months, and 18.6% for between three months and one year (Australian Institute of Health and Welfare. Residential aged care in Australia 2007-2008: A statistical overview. Canberra 2009). Those who stay for longer periods in residential aged care often have dementia.

Most older people express a preference to live and die at home. This can be difficult to access and co-ordinate across aged care and specialist palliative care services. Program boundaries can also limit the support well known services can give existing clients who require palliative care.

Cancer, while core business for specialist palliative care services is not the leading cause of death for older people. For people aged 65 and over in Australia leading causes of death are ischemic heart disease, cerebrovascular disease, lung cancer, chronic obstructive pulmonary disease, other heart disease and dementia (Australian Institute of Health and Welfare. Older Australia at a glance: 4th edition. Cat. no AGE 52 Canberra 2007.) Dementia, while currently the third leading cause of death behind ischemic heart disease and stroke, is increasing in prevalence. From 1998 to 2007 there was an increase by 126% of deaths from dementia related illness (Australian Bureau of Statistics. 2007 Deaths Australia Cat No.3303.0, 2008). It is likely that this trend will continue.

Aged care services should ideally be able to play one of two roles in the provision of high quality palliative care. Services should be able to offer a general palliative approach and facilitate high-quality palliative care to support people to die with dignity and in comfort at home or in a residential facility if they so choose or deliver specialist palliative care services themselves, where appropriate and possible.

Both roles involve:

- having systems, policies and processes in place to allow care staff and case managers to have conversations about dying at the time of service admission with the client/resident and their families (possibly also including doctors and those representing spiritual needs), to clarify values and preferences, and to initiate formal advance care planning processes if required. This may also require staff to advocate for them when communicating care direction and needs with their GP (see case study on the model of multi disciplinary palliative care case conferencing in Appendix one);
- ensuring a basic level of training in and understanding of the palliative approach to care amongst all staff, including training in the ability to recognise signs of imminent death;
- ongoing training and education on palliative care for informal carers as well as paid staff;
- better assistance, training and support mechanisms for informal carers who are supporting a friend or relative with a terminal illness at home ;
- having processes, systems and supports in place to allow care staff or case managers to make decisions at times of sudden change in a person’s condition that are based on their expressed or recorded wishes and values, with a call to the ambulance just one of a number of options, rather than the default and automatic course of action;
- ensuring adequate monitoring and management of pain for all residents/clients; and
- establishing relationships with palliative care specialists.

The Palliative Care Australia *Standards for the Provision of Quality Palliative Care* should be considered as a quality framework for residential or community aged care services. In cases where the aged care provider has become a specialist palliative care service these standards should be applied.

Shifting the balance to home based palliative care

Generally people express a preference to die at home. There is a need to increase the provision of palliative care delivered in the home and create a shift away from unnecessary and undesirable admission to acute care.

As stated earlier Western Australia is very successful in the provision of home based palliative care services. Silver Chain is the sole specialist community palliative care provider for the entire Perth metropolitan area – greater than 5,000 square kilometres with a population of 1.6 million people. The service admits approximately 3,000 people annually, with more than 660 people admitted on any given day, and an average length of stay of 84 days. Sixty (60) per cent of admitted people are supported to die at home (compared to national average of 25-30%). McNamara and Rosenwax (2007) study *Factors affecting place of death in Western Australia*, demonstrated that those who accessed community palliative care were seven times more likely to die in their own home. Recent analysis of Silver Chain data demonstrates that 60% of those who died at home had no hospital admissions during their episode of care with the service, and 28% had only one.

Funding for the service is provided by the WA Department of Health, Department of Veterans' Affairs, donations and bequests. There is no charge for the service, and includes the provision of equipment and medical devices from Silver Chain's supply chain management service, CarePlus.

Silver Chain provides three specific service offerings:

1. ***Metropolitan Community Palliative Care Service:*** Provision of in-home specialist palliative care to clients within the metropolitan area and to all metropolitan care facilities that do not have a registered nurse managing care 24 hours a day.
2. ***Palliative Nurse Consultancy Service:*** Provision of a palliative nurse consultancy service to metropolitan public/private hospitals and residential facilities where client care is managed by a registered nurse 24 hours each day. The service provides specialist nursing advice, assessment, procedures, specific staff education and telephone follow up to meet the care needs of a specific client. Referrals are accepted from medical practitioners, registered nurses and allied health staff that are providing care within the facility. Involvement is limited to a period of five days following which the client is separated from the service. The client can be re-referred and there is no charge to the facility or the client.
3. ***Palliative Rural Telephone Advisory Service:*** Clinical Nurse Consultant Managers who have specialist skills and knowledge provide telephone advice to rural service providers regarding managing the palliative care needs of a specified client. This service is available via a free call telephone number 24 hours per day, seven days per week.

The service is delivered by an interdisciplinary team covering a specific geographical area. Each team is lead by a Case Coordinator (clinical nurse) and consists of registered nurses, social worker, care aides, Chaplains, counsellors, medical staff (specialist, registrar and RMOs), domestic assistance and volunteers. The teams are supported by Clinical Nurse Consultant Managers (CNCM) and on-call Hospice Care Service doctors who are available 24 hours a day, seven days a week. Admission Facilitators (hospital liaison nurses) assist in the referral of complex clients from hospitals to the service and liaise between the team and hospital staff when clients are in the inpatient setting. Bereavement support is provided post death based on the assessed risk level of the bereaved.

The service model is guided by the following principles:

- Integration and service coordination;
- Interdisciplinary care planning;
- Evidence-based, client-centred care.

In comparison to many community palliative care services, Silver Chain's model varies in a number of distinct ways including:

1. **Whole of Metropolitan Service**
    - Improved workforce development and planning across a significant number of staff and disciplines.
    - Improved resource utilisation and allocation.
    - Reductions in administrative overhead and burden.
    - Single point of referral.
    - Population-based approach to service development and planning.
    - Coordinated service provision across specialist, primary care and primary health care where Silver Chain is a major provider in all areas.

2. **General Practitioner Engagement**

    Silver Chain employs 32 General Practitioners across Perth who support each of the eight geographically based care teams. The doctor works closely with the client's general practitioner to discuss and plan ongoing care. The client's general practitioner has the following options:

    - *Full Care*: where the general practitioner is available to the client, family and Silver Chain team 24 hours per day.
    - *Shared Care*: where the general practitioner is available during business hours, while the Silver Chain doctors provide services out of business hours.
    - The Silver Chain doctor is the only medical decision-maker.

3. **24/7 Service**

    The large scale of the service enables staff to be available 'out on the road' to respond 24/7 with shifts that cover day, evening and night, and enables:

    - rapid response to crisis events;
    - planned after-hours support for client, carer and family where required;
    - symptom assessment and management 24/7 at home;
    - back up support (on-call) by senior nursing and medical staff in support of rostered staff; and
    - provision of equipment 7 days a week via CarePlus.

4. **Personal Care and Respite Provision**

    Care Aides are employed as members of each team for the support / provision of personal care at home and respite care. As members of the team, full care provision can be coordinated internally to support the client's wishes to remain at home. Where respite care is provided (average duration of four hours each) in the last weeks of life, 80% of those clients are supported to die at home.

Silver Chain utilises an integrated IT solution across all areas of operation – ComCare. This purposely designed software assist community and residential care organisations deliver a better level of care while reducing costs and improving productivity. All staff utilise hand-held technology allowing access to required information in all environments, supporting care decision-making and delivery, and collection of required clinical information that assists targeted care delivery, internal and external benchmarking activities

This is a comprehensive service and demonstrates that where such a focus is provided people can be well supported to die at home.

Case studies of quality palliative care provision to older people in aged care

The Alliance reviewed the following case studies (Appendix one) to try and understand why and where palliative care works well and how people's preference to die at home can be supported:

- Palliative Aged Care Link Nurse Positions, Victoria (residential care focus)
- Metro South Palliative Care Services RACF PC Service, Queensland (residential care focus)
- Comprehensive Evidence Based Palliative Care in residential aged care (cebparac), Queensland (residential care focus)
- Multidisciplinary Palliative Care Case Conferencing for residents with end-stage dementia, Queensland (residential/dementia focus)
- Hunter Collaborative Palliative Dementia Care Framework, NSW (community, residential and dementia focus)
- Silver Chain Community Palliative Care, WA (community focus)

There is a clear connection between the quality of the palliative care provided, the outcomes for individuals and families, and the existence of good linkages between specialist palliative care services and aged care providers.

These linkages work best when they have been created systemically within a region and are often supported by written agreements between the two organisations. The tangible benefit identified is the access (sometimes 24 hours) to specialist and clinical advice for aged care staff. The Metro South Palliative Care Service in Queensland and the Hunter Collaborative highlight the effectiveness of this approach. The Victorian case study is similar in approach.

Common to these three projects has been:

- Priority and focus given to palliative care for older people/aged care. This has occurred either as a result of the specialist palliative care service operating in an area where there is a large older population and/or high usage of hospital services, particularly by residential care services. Supporting the older person to either stay at home or in their residential care home is better for the person and is a more cost effective option for State Governments.
- Funding, may be one off or recurrent, to support a systemic approach. The relationship and support has to be embedded in ongoing practice.

In discussing the case studies the Alliance also identified that one of the key linked issues for the provision of quality palliative and end of life care at home or in residential care is the ability of staff and informal carers to administer necessary pain medications including syringe driver medications.

There have been projects to provide training to informal carers and to aged care staff in using syringe driver medications and these have been successful in supporting people to die in place.

The other recurring theme for quality palliative care provision is access to ongoing training. The Alliance acknowledged that the Federal Government, and a number of other bodies, have put considerable effort into training development through programs such as *Program of Experience in the Palliative Approach (PEPA)* and *Palliative Care Curriculum for Undergraduates (PCC4U)*. While these are good initiatives the reach is limited (particularly in allied health and medicine) and the high turnover of aged care staff means that it needs to be continually available. These initiatives need to be built on and address the variable quality issues of VET training and barriers to aged care staff take up of the available training and education.

Recommendations

There is a wide range of action that could be taken to improve the provision of palliative care services and these are outlined in Appendix two. The Alliance has a number of priority recommendations which it believes will have the most impact and that should be actioned as part of the aged care reform process:

- COAG discussion and recommendation to make palliative care for older people and aged care service support a palliative care funding priority in 2012-2013. The need for this priority to be created can be tied to its ability to decrease unnecessary, undesirable and costly hospital admissions and usage.
- One off Federal Government funding (to support state action in this area) to create systemic linkages with aged care providers in specialist palliative care services regional boundaries. This would include linkage projects in both community and residential care.
- Changing ACFI requirements – recognising pain may not be present and allowing appropriately qualified staff in the residential aged care facility to direct palliative care provision - for residential aged care services to access palliative care funding. (This could be done in advance of the reform agenda.
- Remove any barriers to an individual's ability to access both community care services (HACC/Packaged Care) and Specialist Palliative care services. This includes having clearer policy and funding guidelines. (This could be done in advance of the reform agenda).
- Ensure the Gateway provides information and support to access on advance care planning and palliative care services.
- Assessment for palliative care to be an integral aspect and skill of Gateway assessors.
- Include specific reference to quality palliative care training in the Productivity Commission's proposed VET review, including whether palliative care should be an elective or mandatory topic.
- Promotion of the palliative care education and training that is already available - including online, short courses, VET and undergraduate - for people to access.

Multidisciplinary palliative care case conferencing for residents with end-stage dementia

Few people living with dementia receive high quality palliative care. A relatively small proportion of people with dementia are encouraged or supported to engage in the process of advance care planning[2]; pain – often chronic and sometimes excruciating – is generally under-recognised and under-treated[3]; and common co-occurring medical complications such as eating difficulties, incontinence or pneumonia[4] often prompt hospitalisation rather than appropriate palliative treatment in situ.

Amongst the many factors that contribute to the poor standards of palliative care for people with dementia are barriers to effective communication, collaboration and planning, particularly between GPs, residential care staff and family carers.

One model of end-of-life care that has been shown to work successfully in Australia is the model of multidisciplinary palliative care case conferencing (MMPC) for residents with end-stage dementia. This model is based on the Australian guidelines for a palliative approach in residential care, and can be readily implemented within a framework of multidisciplinary care such as that provided by the MBS Primary Care Items (formerly the Enhanced Primary Care Program), involves an intervention that brings together the family of the person dying with dementia, the residential aged care facility staff and the GP to:

- discuss the medical and personal history of the person with dementia;
- identify and address carer concerns, and agree on the need for a palliative approach;
- identify the person's multidisciplinary care needs, agree on goals of care, and establish a plan for multidisciplinary care; and
- implement and regularly review the plan as the dementia and other comorbid conditions progress, up to and including the death of the person, and continuing provision of appropriate support to both family and staff thereafter.

The approach was subject to a rigorous evaluation in 2004-05 with generally positive results. Amongst the many benefits observed were increased satisfaction of staff and family carers, increased confidence of care staff to provide palliative care, pain and symptom control improved, and the case-conferencing approach was shown to be viable and effective. Implementation of this model, while possible under existing payment frameworks, does require a commitment from both GPs and from residential aged care facilities to engage in the process, and to provide adequate training and support for staff.

How this works for an individual - Judith

Judith, aged 92 and with a diagnosis of Alzheimer's disease, had been living in a residential care facility (RACF) for eight years. At the time of her admission into the facility, her record indicated additional conditions including arthritis, chronic constipation, a history or urinary tract infections, urinary retention, a fractured pubic ramus, depression and paranoid delusions. During her time in the RACF, she had a history of resistive and aggressive behaviours and had experienced neurological episodes which were labelled 'turns' by RACF staff.

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[2] Nair, B. et al. (2000). Advance care planning in residential care. Internal Medicine Journal, 30(3), 339-43.

[3] Herr, K., Bjoro, K., Decker, S. (2006). Tools for assessment of pain in nonverbal older adults with dementia: A state of the science review. Journal of Pain and Symptom Management. 31(2), 170-192.

[4] Mitchell, S. et al. (2009). The clinical course of advanced dementia. New England Journal of Medicine 361(16), 1529-1538.

Judith was of ethnic origin and did not speak English. However, her family lived locally and a close relative was listed as her next of kin. Judith did not have an Advanced Health Directive, Enduring Power of Attorney or documented funeral wishes.

By the time the researchers met Judith, she had been in the facility for seven years. Her neurological episodes were increasing in frequency, and had been gradually declining. She was assessed as being resistive to care, immobile, requiring full assist with activities of daily living and was unresponsive at times. She had difficulty swallowing and was on a soft ethnic diet with thin fluids. There was an unconfirmed report that Judith may have experienced a TIA.

A model of multidisciplinary palliative care conference (MMPC) was conducted in August 2005 with nursing staff, research staff, the General Practitioner and family members. Matters that were discussed included nutritional needs, pain management, family and spiritual requirements, and in particular, the specific cultural needs in regard to Judith's body preparation at death. The family were provided with the opportunity to ask questions or to seek clarification on any aspects of care provision or of their relative's condition. They were also asked to advise staff on any special wishes regarding end of life care.

The main outcome from the MMPC was clarifying and agreeing on end of life needs by all members of the MMPC team, including family. The decisions made related to not force feeding, providing adequate pain relief, notifying the family when death was imminent, and complying with specific cultural requirements according to the family directive.

The family were aware of their relative's deterioration, noting that "*last Saturday Judith didn't recognise my sister*". A family member also commented on the length of time (eight years) that their relative had been in an RACF, "*I heard that the average time in a nursing home was 1-2 years….it is very prolonged although there is no quality*", adding, "*we really appreciate the care that you are giving Judith*".

Almost three weeks before she died Judith's condition was 'poor'. Her family were notified of her condition when she was transferred to the Palliative Care room. Nursing staff initiated the Palliative Care Plan that had been agreed during the MMPC with domains including physical care needs, pain relief, associated therapies, family requests, family participation, pastoral care, emotional support and environmental needs. Her legs were gently massaged to improve circulation and soothing music calmed the environment.

Judith stabilised and twelve days before she died was transferred from the Palliative Care room back to her 'old room'. When queried about the transfer staff replied, "*Because she didn't die. We usually only keep people in the palliative care room for one or two days*". Judith had started to eat a little and staff reported that there was another resident with a higher need of the dedicated Palliative Care room.

Over the next week Judith was kept comfortable with regular subcutaneous morphine, and did not require any additional morphine for breakthrough pain. Five days before her death, Judith was no longer taking food or fluid, and as agreed, there were no efforts to force feed. Oral medications were ceased, but mouth and eye toilets were maintained.

Pressure area care was paramount and pressure ulcers on her buttock and coccyx were dressed regularly. Several devices were employed in an effort to reduce pressure on Judith's fragile skin including a pressure relieving mattress, pressure relieving gel booties, a heel wedge and the use of barrier creams. Two days before her death, Judith's extremities were cyanotic and cold to touch; she was peripherally 'shutting down'. A large amount of exudate oozed from Judith's ulcerated coccyx on the day before she died.

She died peacefully the following day less than three hours after being transferred back into the Palliative Care room. Her body was prepared according to the specific cultural needs that had been discussed during the case conference, and staff were given the opportunity to attend Judith's funeral.

Key reference

Abbey, J., Douglas, D., Edwards, H., Courtney, M., Parker, D., Yates, P. (2008).Final Report: Develop, trial and evaluate a model of multi-disciplinary palliative care for residents with end-stage dementia. (Funded by The Prince Charles Hospital Foundation 2005) February 2008, Brisbane.

Hunter Collaborative Palliative Dementia Care Framework (HCPDCF)

This project was built on an existing and very successful model of delivering a palliative approach to older people in residential and community aged care services within the Hunter. Palliative ***Aged*** Care in the Hunter is very much a nurse driven model and there were three key elements that provided a solid base for the HCPDCF project:

1. **Funding though Federal local Palliative Care Grant Program (LPCGP)** for rounds 1, 3 (Catholic Care) and 5 (HNEAH) - both organisations being key members of the Hunter Aged Palliative Care Network (HAPCN). The National Guidelines for a Palliative Approach in Residential Aged Care supported the development of relevant, evidenced based nursing ACP resources that were more aged care friendly.
2. **Leadership of the Hunter Aged Palliative Care Network (HAPCN)** in promoting a person centred and truly collaborative, interagency approach to sharing of resources, education delivery and nurse led clinical expertise and mentoring. Development of the Website for easy access to resources www.hapcn.com.au.
3. **Commitment of Hunter New England Local Health District** to Advance Care Planning and promotion of quality end of life care for older people. HNEH funded a broader education initiative led by Dr John Ward working within residential aged care facilities delivering hands on ACP education workshops and providing quality resources – a toolkit of resources to support quality ACP discussion was distributed to all facilities.

Using these existing resources that were well accepted and validated throughout aged care in the Hunter, the round five project launched straight into implementation through a fully funded champion model of nurse led practice. Aimed at educating and empowering nurses to have the difficult conversations around prognosis, death and dying and become advocates for their elderly residents in quality end of life decision making for natural dying.

The framework delivers eight key areas of focus. Organisations were encouraged through their fully funded champions, to take up any area they felt was manageable within their facility/ies. A management representative from each organisation was expected to sit on the Advisory Group and this was integral to the success of the project. Facilities were provided with of a range of printed and validated resources, comprehensive and aged care friendly education sessions, and access to clinical nurse mentors and membership of HAPCN. Champions met monthly for education, peer supervision and reflective practice development.

Four primary focal points were identified as requiring a multidisciplinary approach from a range of health professionals - these being: **Prognostication: Legal and Ethical: Advance Care Planning: and End of Life Care**. Acknowledgement was given to a core principle that no one health professional could approach all these topics with the depth of knowledge, objectivity or skill level that was required to support a person transitioning from curative to a palliative approach or making treatment and care choices.

Framework areas:

1. **Diagnosis and recognition** that Dementia is a life limiting condition (utilising UWS Dementia resources – this also built on previous work around chronic disease trajectories).
2. **Resourcing and informing** older people entering aged care services and their families, about the benefits of having a discussion around advance care planning. Also providing opportunity for this to occur with informed and empathetic staff who focus on care choices as well as treatment options.
3. **Assessment of pain** – recognising that older people have different pain and that people with dementia often do not express pain in ways that the general population do. Provision of tools to empower carers to collect evidence of pain so they can advocate for good pain management.
4. **Advance Care Planning** – providing tools and practice workshops to support discussions that that were more care and comfort focussed not necessarily treatment focussed in the first instance.
5. **Prognostication** – recognising dying as a longer process in a person with dementia and providing tools to give better prediction of EoL – promoting quality of life choices and advocating for families with doctors around futility of treatment decisions.
6. **MOLST** - providing a one page hospital/ acute care medical order for treatment decisions should a person need to enter the acute care system or have a visiting LMO at the service. (*Appendix two*)
7. **Implementing and End of Life Care Plan** - for care delivery at end of life (Brisbane RACEoLCP used).
8. **Post Death Support** - recognition of complex grief, support and referral pathways.

Following this project six of the eight participating organisations have retained a paid palliative care champion; all have adopted every aspect of the framework. 90% of residents have an advance care plan in all facilities within five of the seven organisations. There has also been a significant (data not yet available) reduction in hospital admissions from facilities involved in the project and all facilities are reporting an increase in people dying comfortably within their aged care facility.

The biggest barrier to quality End of Life care that presented was the shortage of registered nurses available for adequate pain and other symptoms assessment and effective pain and other symptoms management, especially in low care facilities who are ageing in place.

Advance care discussion conducted by nurses has been very well accepted by residents and their families.

The model is also being taken up in the Newcastle and Lower Hunter ACAT where comprehensive assessment is now including provision of information to start the ‘discussion’ and in some cases completion of an ACP.

The project has greatly enhanced communication with the acute care sector in regards to end of life treatment and decision making and improved understanding of the complexity within the aged care sector in regards to ‘low’ and ‘high’ care facilities and variations in registered nurse coverage.

Specialist palliative care services have requested education around dying and dementia and are now engaging more with the aged care sector on the differences in dying from a chronic disease and dying with cancer related disease processes.

An unplanned outcome was the high level of family satisfaction and expressed reduction in grief experienced by family members following a 'natural' death that was well supported by the multidisciplinary framework approach.

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Resources available at www.hapcn.com.au

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Workforce initiatives to further develop capacity in the palliative care approach in aged care services, consistent with the evaluation of *Strengthening Palliative Care: a policy for health and community care providers 2004-2009*, which recommended that the government assist residential aged care services to care for people at the end of life by strengthening resources (in metropolitan and rural regions) to support aged care, are now being actioned.

Funding of $770,000 in 2011-12, $622,000 recurrent from 2012-13 was identified in the 2011-12 state budget to employ eight palliative care/aged care link nurses across Victoria (one in each departmental region).

Strengthening palliative care: Policy and strategic directions 2011-2015 (released in August 2011) includes an action (3.6) to establish an aged care palliative care link nurse in each region. The impact associated with this action is the implementation of end of life care pathways in residential aged care facilities.

An associated action in the policy (3.5) is to undertake a statewide project to establish protocols and strengthen relationships between palliative care and aged care services. The impacts associated with this action are the development of state and regional palliative/aged care action plans and the development of joint resources to support the provision of end-of-life care in aged care services.

The funding is based with the palliative care consortia in each region. We have recommended that the link nurse position be based with a palliative care consultancy service as part of a multi disciplinary team and that the position work across each region (ie not specific to a health service). The scope for the positions includes public and private aged care facilities and high and low care facilities.

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A comprehensive evidence based model of palliative care in residential aged care (cebparac)

Under the Department of Health and Ageing EBPRAC program the UQ/Blue Care Research and Practice Development Centre developed and implemented an evidence based model of palliative care in residential aged care facilities using the NHRMC endorsed guidelines for a palliative approach in residential aged care.

This model involved three key processes of care (advance care planning, palliative care case conferences and an end of life care pathway) and assessment and management strategies for five main symptoms experienced by older people at the end of life and the use of link nurses or champions. The model was evaluated in nine RACFs over four states in Australia using a pre/post design. A total of 73 residents received the new model of care and their care was compared to 83 residents who had died in the nine RACFs prior to the new model of care. Chart audits were completed on the last month of care for residents in the pre and post sample. There were significant improvements in documentation of end of life (EOL) wishes (55.4 vs 72.6%), evidence that next of kin were involved in EOL discussions (71.1 vs 95.7%), the use of palliative care case conferences (8.4 vs 94.5%) and an

EOL care pathway (21.7 vs 84.6%, $\chi 2$). There was a significant improvements in pain assessment (41.6 v 70.3%), effectiveness of non-pharmacological treatments for pain (23.4 v 62.5%), effective use of regular analgesia (56.7 v 64.5%) and prn analgesia (62.1 v 77.6%). Significant increases were also found for assessment of dysponea (2.4 v 44.4%) and the use of non-pharmacological strategies for dysponea (31.7 v 57.1%). The model was positively evaluated by staff at all levels. Of the 42 residents who died in the study, 41 (95%) died in the RACFs.

To ensure the model could be adapted to other RACFs an education toolkit for staff which provides a step by step approach to implementing a palliative approach in has been developed. **This Palliative Approach Toolkit** so far has not received funding for wider distribution beyond the original facilities involved in the project. See the following website for details of the Toolkit. http://www.uq.edu.au/bluecare/the-palliative-approach-toolkit.

Reference

Parker et al 2010 (Implementing and evaluating a comprehensive model of palliative care in residential aged care facilities. Report to Department of Health and Ageing). Available for download http://www.uq.edu.au/bluecare

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Other palliative care improvement actions

Specific aged care related action required

National implementation plans/support to implement evidence based resources such as the Palliative Approach Toolkit in Residential Aged Care and the recently released Community Palliative Care Guidelines. This would include ongoing training being available.

Access to home based respite particularly overnight respite.

General palliative care related action required

Community education which continues to promote general discussion and awareness of the issues around death and dying, particularly in terms of the importance of advance care planning and power of attorney. Such education would help to drive change as people become aware of, and exercise, their choices in dying with dignity.

Advance Care Planning promotion at key times when people may be open to having such a conversation – for example health checks, licence renewal process for a 75 year old, when making out a will and on a drivers licence (in the same way as organ donation).

Funding for more community based palliative care services. This is done very well by groups such as Silver Chain in Perth who receive adequate state government funding; (incorporates provision of direct care services; and, provision of statewide consultancy services to acute, aged care and primary providers 24/7) few other states provide similar levels of funding.

Extend funding for equipment - One off funding was provided to Palliative Care Australia (funded until June 2012) to go towards the purchase of equipment to be loaned to patients as the provision of care in the home can require specialised equipment.

Adequate funding of community specialist palliative care services to provide education and consultation services, ensuring they are 24/7. This is a critical issue as it has been well demonstrated that access to such support empowers informal carers, community staff and Residential Aged Care Facility staff to feel able to continue to provide palliative care at home or in RACF's.

Further funding is required to develop, demonstrate and implement palliative care pathways. A number of such projects have been funded through Government programs to date (including the local palliative care grants and the Encouraging Best Practice in Aged Care Initiative). A commitment from Government is required to take the results of successful projects, and roll them into new or existing national programs.

Further education to increase basic understanding about palliative care is required across the health care spectrum, and should be integrated into undergraduate and certificate level programs for all health and aged care professions. There should also be infrastructure and funding for education to be provided for rural, remote and regional delivery of palliative care training and education to assist in up skilling aged care staff.

Education and Training for GPs to better recognise and identify that people are likely to die in the next 6-12 months, and provide referral mechanisms to ensure that these people receive palliative care.

Education and training for informal carers

Hospital admission processes that recognise imminent death, and place importance on discharging the person to allow them to die in their own home. A systematic evaluation of the economic and care quality costs of unnecessary hospital-based medical intervention at end-of-life would highlight some of these issues and may help to prompt changes.

Use of telehealth for clinical and carer support provision in all areas where this service is available but in particular in rural areas where access to specialist palliative care is limited.