PCAG Agenda Item 6.1 NSW HEALTH

Meeting Date	4 August 2010
Agenda Topic	Improving care options for palliative patients at risk of admission to Residential Aged Care Facilities
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Palliative Care NSW have endorsed the following set of recommendations and have promoted them to Palliative Care Australia. They have also been forwarded to the Australian Government Dept of Health and Ageing (DOHA).

Introduction
Following several years of research into the impact of transfer from Palliative Care Units to Nursing Homes, and at the conclusion of a DOHA funded project to develop a new model of care in this area, Julie Garrard convened a National Workshop on the Transition from Palliative Care to Residential Aged Care at Calvary Health Care Sydney on 2nd March 2009.

The following recommendations emerged from a vigorous discussion and several formal presentations at the full day workshop. This was attended by senior clinicians from 11 Palliative Care Services in NSW, ACT, Victoria and South Australia, as well as representatives from SCIP, NSW Health, DOHA, Palliative Care NSW and the Director of 2 Aged Care Facilities in Southern Sydney (attendance list appended). The workshop's original purpose was to develop a best practice model for Palliative Care Services in Australia regarding the transfer of palliative patients to aged care facilities but several recommendations also emerged for better care options at home for this group.

The recommendations:

1. Palliative Care Packages for Community Care
According to the literature, patients and families commonly express the wish to have their palliative care at home and wherever possible to die at home. The lack of available, appropriate and timely services often means patients and carers cannot achieve this goal. Tailor-made short term packages of care were recommended.

We propose a new ACAT assessment category for the Aged Care Client Record (ACCR or 3020 form) and funded model of care option based on the Palliative Care Extended Aged Care at Home Packages (PEACH packages) currently being piloted and evaluated in SSWAHS . This project is due for completion later in 2010. The aim of this package is to better meet the needs of palliative care patients who require extensive services at home, but who have a relatively short prognosis, usually up to 3 months.

These packages would be designed to provide an affordable care option at home for patients requiring high level care. The package of care will be similar to the current federally funded EACH packages but will be tailored to meet the shorter term needs of patients who may have intense care needs at the end of life. An important requirement for these care packages is immediate availability, as Palliative Care patients often die while they are on the long waiting lists for EACH packages or are not even placed on the waiting lists due to their short prognosis. Also the lower age limit of 65 should be waived for this patient category.

These packages may need to be jointly funded by DOHA and relevant State Departments, including NSW Health.

2.Admission to and discharge from palliative care units
Palliative Care Units (PCUs) are not long term facilities in the way that Hospices used to be. This requires careful criteria to be applied re admission and discharge.

2.1.Pre-Admission Stage
Pre-admission assessment is according to agreed criteria for the PCU. Assessment of suitability for admission to the PCU is conducted by a specialist palliative care health professional who can clarify goals of the transfer to PCU, and reinforce to patients and families that the PCU is "not a long term facility".

2.2.Discharge Planning to RACF
Estimating prognosis for palliative care inpatients can be challenging when planning for discharge to a RACF. It is distressing for all involved when the patient dies quickly after discharge to a RACF, according to research by Julie Garrard at Calvary Health Care Sydney (as yet unpublished, but widely presented at Conferences) .

It is recommended that a validated prognostic tool be used when determining suitability for discharge to a RACF. Clinical research conducted by Dr Corey Lau and colleagues at Canterbury Hospital has shown the usefulness of using a prognostic tool such as the PaP score on admission and again within 2 weeks following admission to the PCU. This improves accuracy in prognosticating for discharge to RACF.

The decision to discharge from a PCU to a RACF should take account of the patient's likely prognosis, current and likely future symptoms, and a psychosocial assessment of the patient's and carer's ability to adapt to the transition to ACF

3.Options for Longer Term Care

3.1. Step down facility
Some palliative care services have the option to transfer patients from their PCU to a "step down" facility on their own campus (such as the Mercy Hospital in Albury and Greenwich Hospital was in the planning stage for same). These may be RACF beds or transitional care beds or some combination of federal Aged Care and state Health funding. This was seen as an ideal option available as there can be a continuity of care provided and the patient and family will not suffer the stress of relocation to the same degree.

3.2.Partnership with local RACFs.
A number of PCUs/services attending the workshop had entered formal partnerships with local RACFs, and the evaluations to date were very successful. Such partnerships offer benefits to patients and carers, the PCUs/services and the RACFs in terms of improved access to RACF beds and the development of increased expertise in the palliative approach for RACF staff.

These partnerships need to be based on the likelihood of a successful relationship, high level of interest in palliative care by the RACF(including GP's) and good access to beds as needed. A formal Service Agreement is required between the partners

3.3.Follow up care in RACFs

Specialist Community Palliative Care Teams should provide regular visits to the patients discharged to RACFs during the initial 12 weeks after transfer to ACF but for most Specialist services this is unrealistic due to already high caseloads. The Community Palliative Care team is multidisciplinary and co-ordinates visits according to resident and family carer need. Close liaison between visiting team members and RACF staff will ensure continuity of care during the transition period. Liaison with GPs is also required for pain and symptom management issues and to formalise the patients future care plan. Medicare EPC Item No.'s may be used for this.

The Community Palliative Care visiting at RACFs should include multidisciplinary team members such as :

- Community Palliative Care Nurse
- Social worker*
- Volunteer*
- Pastoral care worker
- Palliative Care Staff Specialist or registrar

Referral for Bereavement follow up after the resident dies should be standard.

**Julie Garrard's research has demonstrated the value of psychosocial support during the transition period.*

3.4. Resource implications

Community palliative care teams already carry heavy case loads. To ensure effective follow up of patients discharged to RACFs from PCUs we recommend:

1.increased funding to these teams to employ at least an extra 0.2 FTE community nurse specialist. This will cover the extra referrals to the community team which arise as a result of their regular visits to RACFs and the consequent requests for education in RACFs.

2.We would also recommend funding of at least an extra 0.1 FTE social worker to ensure the psychosocial needs of these transferred patients and their carers are assessed and met during the transition period, which is known to be a high stress period. Most RACFs do not employ social workers, but recent research by Calvary Health Care Sydney has demonstrated how significant this can be.

4. Palliative Care Residential Respite Care: we propose a new ACAT assessment category for the Aged Care Client Record (ACCR or 3020 form) to better meet the needs of palliative care patients who require residential care (RACF) and who have a relatively short prognosis, usually up to 12 weeks. This will be called "Palliative Care Residential Respite Care".

Patients transferring from a Palliative Care unit to a high level RACF usually have a short survival time in the RACF, (based on research by Julie Garrard and other researchers). Given this fact, these patients would benefit by being assessed initially as requiring residential aged care on a "Palliative Care Residential Respite Care" basis. This would allow the same conditions that residential respite admission in a RACF currently provides in terms of payment of a fixed daily fee only, but would need to be subsidised by the Australian Government at the rate for a resident with complex palliative care needs according to the ACFI, i.e. the highest level.

This respite status could be time limited to the current 9 weeks or ideally extended to 12 weeks. After this transition period at the RACF, if the resident is still alive, they would be re-assessed for permanent status and all the necessary paperwork will then have to be completed,

including the Centrelink assessment of fees. However it is expected from the evidence that the majority of such residents would have died within this period.

This option will make it easier and more attractive to RACFs to admit palliative patients being transferred to RACFs from hospitals or Palliative Care Units, where the prognosis may be short. It will also reduce the burden on family carers to complete onerous paperwork for Centrelink and the RACF in the early weeks following transition to an RACF.

A further recommendation is that the lower age limit of 65 would not apply for this assessment category, as at times younger palliative care patients require residential care which is only available in RACFs. The workshop also highlighted the urgent need for more age-appropriate residential care options for younger patients.

Appendices to follow :

1.Summary of Responsibilities arising from Recommendations

2. List of Participants in the National Workshop on the Transition from Palliative Care to Residential Aged Care held at Calvary Health Care Sydney on 2nd March 2009

Please contact Julie Garrard, Senior Social Worker, Calvary Health Care Sydney on 9553 31111 or email her at julie.garrard@sesiahs.health.nsw.gov.au for further information

APPENDIX 1

Summary of Responsibilities arising from Recommendations for Improving care options for palliative patients at risk of admission to Residential Aged Care Facilities

Recommendation 1
That Palliative Care Packages for Community Care at the end of life be funded and rolled out. These packages of care will be informed by the DOHA funded pilot work completed in SSWAHS

Primary Responsibility
Australian Dept of Health and Ageing, ACATs

Other agencies
NSW Health, other relevant NSW Government Depts, Palliative Care Service providers

Recommendation 2.1
That assessment of suitability for admission to the PCU is conducted by a specialist palliative care health professional who can clarify goals of the transfer to PCU, and reinforce to patients and families that the PCU is "not a long term facility".

Primary Responsibility
Specialist Palliative Care Services (SPCS)

Other agencies involved
Acute hospitals and GPs referring to SPCS, RACFs

Recommendation 2.2
That a validated prognostic tool be used when determining suitability for discharge to a RACF.

Primary Responsibility
Specialist Palliative Care Services (SPCS)

Other agencies involved
Acute hospitals and GPs referring to SPCS, RACFs, Australian Dept of Health and Ageing

Recommendation 3.1
That palliative care services have the option to transfer patients from their inpatient Palliative Care Unit to a "step down" facility on their own campus, which provides a level of care between specialist palliative care and residential aged care.

Primary Responsibility
NSW Health, Palliative Care Service providers

Other agencies involved
Australian Dept of Health and Ageing

Recommendation 3.2
That palliative care services enter formal partnership with local RACFs which offer benefits to patients and carers, the PCUs/services and the RACFs in terms of improved access to RACF beds and the development of increased expertise in the palliative approach for

Primary Responsibility:
Specialist Palliative Care Services (SPCS)

Other agencies involved:
RACFs, Australian Dept of Health and Ageing

Recommendation 3.3
That Specialist Community Palliative Care Teams should provide regular visits to the patients discharged to RACFs during the initial 12 weeks after transfer to RACF . This should be by members of the multidisciplinary team who are funded to provide this service.

Primary Responsibility:
Specialist Palliative Care Services (SP CS), NSW Health

Other agencies involved:
RACFs, Australian Dept of Health and Ageing

Recommendation 3.4
That increased funding to these teams be provided to employ at least an extra 0.2 FTE community nurse specialist and at least a 0.2 FTE social worker to provide these services to RACFs.

Primary Responsibility:
Specialist Palliative Care Services (SP CS), NSW Health

Other agencies involved:
RACFs, Australian Dept of Health and Ageing

Recommendation 4
That a new ACAT assessment category for the Aged Care Client Record is included to better meet the needs of palliative care patients who require residential care (RACF) and who have a relatively short prognosis. This will be called "Palliative Care Residential Respite Care".

Primary Responsibility:
Australian Dept of Health and Ageing, ACATs

Other agencies involved:
RACFs

APPENDIX 2

List of Participants in the National Workshop on the Transition from Palliative Care to Residential Aged Care held at Calvary Health Care Sydney on 2nd March 2009

Name	Service/Organisation
Dr Frank Brennan	Calvary Health Care Sydney, SESIAHS
Stewart Clarke	Sacred Heart Palliative Care Service, SESIAHS
Kay Cooper	Clare Holland House Canberra
Dr Elspeth Correy	Braeside Hospital, SSWAHS
Claire Duane	Calvary Health Care Bethlehem, Melbourne
Raelene Elliot	St George Division of General Practice
Julie Garrard	Calvary Health Care Sydney, SESIAHS
Nicole Girotto	Sydney South West AHS Palliative Care Service
Anna Haebets	Calvary Health Care Bethlehem, Melbourne
Ian Hatton	Statewide Centre for Improvement in Palliative Care (SCIP)
Linda Hansen	Palliative Care NSW
Janeane Harlum	Sydney South West AHS Palliative Care Service
Joe Harrison	NSW Dept of Health

Susan Hearn	Hope Health Care North, NSCCAHS
Pauline Heath	Mercy Health, Albury ~~Greater Southern AHS~~
Vivienne Hogg	Canterbury Hospital Palliative Care Service, SSWAHS
Lorraine Knight	Pacific Heights & Rockdale Nursing Homes
Julie Kulikowski	Clare Holland House Canberra
Dr Judith Lacey	Calvary Health Care Sydney, SESIAHS
Dr Gerry Lake	Hope Health Care North, NSCCAHS
Dr Corey Lau	RPAH & Canterbury Hospital Palliative Care Service, SSWAHS
Dr Philip Macaulay	Sacred Heart Palliative Care Service, SESIAHS
Trish McKinnon	Sacred Heart Hospital, SESIAHS
Helen Moore	Calvary, Health Care Sydney , SESIAHS
Dr Michael Noel	Palliative Care, Sydney West Cancer Network, SWAHS
Dr Dennis Pacl	Clare Holland House Canberra
Jenny Richards	Daw House, Adelaide
Sue Schio	Dept of Health & Ageing
Maria McIlwain	Calvary Health Care Sydney, SESIAHS
Jane Hogan	Calvary Health Care Sydney, SESIAHS