

Palliative Aged Care
Network PACN (NSW)
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The Hon Jillian Skinner MP
Minister for Health
Level 31 Governor Macquarie Tower
1 Farrer Place
SYDNEY NSW 2000

Dear Minister

PACN (NSW) is an informal network of Advanced Practice Nurses and Allied Health Professionals with a strong commitment to the principles of palliative care, working within the aged care sector. As a group of senior registered nurses (RN's) employed by a variety of Aged Care organisations in NSW, we believe we bring unique insight to the issue under discussion. Each of our nursing roles involves the support of Residential Aged Care Facility (RACF) staff to provide care for the increasing number of residents with complex care needs through their often increasingly protracted palliative and end of life care journey.

I am writing to you on behalf of our membership which has expressed great concern regarding the legislative 'loop hole' challenging the current requirement for Aged Care Organisations to provide a minimum of one Registered Nurse (RN) per shift, 24/7 in NSW RACF's.

Changes in RACF structure and the move toward older Australians "Ageing in Place", encourages residents to continue to live their lives in their 'choice of place' and remain in their 'home' (RACF) as they approach and reach the end of their lives. It is our belief that these Aged Care Industry changes require the appropriate level of clinically skilled RN's to manage the increasing complexity of symptoms and care needs that are now more commonly experienced by residents in all RACF's. Without 24/7 RN coverage the management of resident's increasingly complex and rapidly changing care needs cannot be adequately supported in the RACF. Resident safety and comfort will be compromised, with a resulting increase in resident transfers to acute hospitals, particularly out of hours and reliance on the NSW Ambulance Service.

As older Australians are living longer with increasing health care complexity RACF staff are being called on by Palliative Care Units and Acute Care Hospitals to provide ongoing Palliative and End of Life Care for patients with increasingly complex care needs.

Care stories from PACN members highlight the increasing acuity of RACF residents:

Care Story 1:

A 75 year old lady with metastatic pancreatic cancer and significant abdominal ascites had a Pleurex tap in place (semi -permanent abdominal drain) requiring second daily drainage by RN's. This procedure must be carried out using strict aseptic technique. Without an RN on duty this lady would have required admission to the acute hospital. The local community nursing team were unable to provide visits for second daily drainage. By up skilling the RACF RN's to undertake this procedure and perform the regular clinical assessments necessary, this lady was able to remain in her 'home' where she had lived for several years, maintaining her comfort and controlling her symptoms. This option would not be available without the presence of an RN 24/7.

Care Story 2:

An 86 yr old lady who lived independently for many years in a retirement village was well known to RACF staff. She was diagnosed with an advanced metastatic bowel cancer that completely blocked her large bowel. From the outset the goal of care was palliative/ comfort care. She underwent an operation to create a stoma (external bag) high up on her abdominal wall to bypass the blockage, reduce her vomiting and pain and give her and her family time to come to terms with this situation. The hospital Palliative Care team worked diligently to offer a plan of care to maximise comfort and manage these symptom complexities, particularly her very high volume liquid bowel output. Consequently, because she was unable to continue to live independently in her unit a request was made to the RACF, where she was known and loved, to be admitted for End of Life Care. It was not possible to implement some of the comfort care strategies advocated by the palliative care team, particularly subcutaneous fluids, as the RACF did not have the 24/7 RN cover to support this request.

Care Story 3:

One night two different residents had a fall at approximately the same time, 0400 hours. The care staff helped both of these women get back into their beds by manually assisting them to stand and transfer. At 08 00 hours the Manager /RN came on duty and was informed of the two incidents that had occurred over night. The RN went to review the two residents. When she pulled back the bed linen and examined each of them in turn she found that both of them had sustained a fractured femur. The clinical signs were obvious to her trained eye. Neither woman had been given any pain relief medication during the night. Both residents were subsequently transferred to hospital and underwent surgery to repair fractured neck of femur.

Care Story 4:

In a low care facility without 24/7 RN coverage a resident suffered a respiratory arrest. This resident had an Advance Care Plan which indicated that she was Not for Resuscitation and that her goal of care was Palliative/comfort care. The facility care staff on duty that night called 000 as they 'didn't know what to do'. The ambulance officers who attended did not follow the Advance Care Plan and instructed the care staff to commence resuscitation. The care staff reported hearing 'ribs breaking' as they attempted to resuscitate her. The resident never regained consciousness and died in hospital in a Coronary Care Unit 10 days later. If an RN had been on duty an ambulance would not have been called and the resident would have had her wishes upheld, dying in "her home" with dignity.

Care Story 5:

In a rural low care facility without 24/7 RN cover the DON (Facility Manager) and DDON (Care Manager) take turns to be on-call and drive in (approximately 30 mins on country roads) when a resident requires a Schedule 8 medication regularly or PRN (when necessary) after hours. For one resident a syringe driver (continuous subcutaneous medication infusion device) was used to provide a continuous infusion of medication ensuring more consistent symptom management and reduce the need for PRN medication after hours with no 24/7 RN. If and when the Syringe Driver faults or alarms the care staff must turn the pump off and again call the Facility Manager to return to the RACF out of hours. This occurred in two instances resulting in the resident being without timely access to pain and symptom management medication for an extended period of time.

Care Story 6:

A 55 year old woman diagnosed with younger onset Alzheimer's disease was in the end stage of her disease process. The resident was nursed in the dementia specific unit and her husband and family requested that she remain in the Low care RACF and be given all comfort care. The dementia unit had access to part time RN coverage available from the nursing home across the road. The resident had been prescribed a pain patch and regular Panadol, with PRN oral opioid medication for symptom control. In late afternoon the resident became increasingly agitated and distressed and care staff requested RN support to provide PRN medication to reduce symptoms and provide comfort. Family were in attendance and all comfort measures that could be attended were done by both care staff and family. The RN informed the team she was unable to attend the resident due to acuity in the nursing home and no bed was available in the nursing home for the resident to be transferred into. The care staff/ team leader called the GP to ask for urgent review but he was unable to attend for several hours. The resident became very distressed, thrashing and screaming out in pain and anxiety. The family were so upset they requested the resident be urgently transferred to hospital for pain and symptom management. The care staff/team leader organised the residents transfer and informed the on-call RN by telephone. The family called the facility two days later to inform them that the resident had died in hospital.

Care Story 7:

An 86 year old gentleman shared his double room with his elderly unwell wife of 65 years in a low care facility. He had a diagnosis of Chronic Obstructive Pulmonary Disease, Asthma and Depression. His quality of life had been deteriorating with more frequent exacerbation of his disease, increasing hospitalisations and the more active treatment options becoming less effective. Care planning discussion with resident, family and GP were undertaken in facility and the agreed palliative approach to his care involved trialling small dose oral opioid medication 3 -4 times a day for his dyspnoea (breathlessness). An RN was required to closely monitor the efficacy of this medication until this gentleman adapted to it reducing the likelihood of side effects. The immediate- release oral morphine could then be converted to an oral long acting opioid medication. Without the RN closely monitoring, administering and evaluating the efficacy of the Schedule 8 opioid medication the resident would have required admission to hospital or worse, not have his symptoms appropriately managed.

There are many other care stories that can be reported by members of the Palliative Aged Care Network (NSW). It is no longer satisfactory to rely on the 'goodwill' of the RN Facility Managers/Care Managers in NSW RACF's. We believe that an RN 24/7 in NSW RACF's is imperative and that the current legislative 'loop hole' must be CLOSED.

Thank you for the opportunity to present our concerns about 24/7 RN coverage in NSW RACF's. The PACN (NSW) membership would value the opportunity to speak to you further about this important issue.

Yours sincerely,

Bronwyn (Bron) Heron

PACN (NSW) Chairperson/ Palliative Care Clinical Nurse Consultant

19th June 2015