



South Island Alliance - PALLIATIVE CARE WORKSTREAM

Survey Report - Aged Residential Care

Introduction

An 18 question survey was sent to all Aged Residential Care (ARC) facilities in the South Island identified through the New Zealand Aged Care Association (NZACA) using Survey Monkey. Thirty four responses (34) were received out of a total mail out of 170 which is a response rate of 20%. Approximately 24 facilities in the South Island are not members of the NZACA so did not receive the survey.

In New Zealand, ARC facilities are privately owned and contracted to provide residential care by the Ministry of Health. There are four categories of facilities. Below are indicative definitions of these categories;

- **Rest Home:** Those who require this level of care usually have some ability to mobilise on their own or with limited assistance. They usually require help with personal care and general day to day activities. Many have a degree of memory loss. There is a Registered Nurse on site some of the time, and on call 24/7. Some people who have dementia may be able to be safely and appropriately supported in a rest home.
- **Secure Dementia Rest Home:** These facilities provide a secure home for those with dementia and for whom there are safety concerns and possible behaviour issues. It is similar to Rest Home care, but the environment is secure and there is a higher level of supervision e.g. for monitoring food and fluid intake. More robust diversional therapy and activity programmes are provided.
- **Hospital Level:** Hospital care is provided for those who have a significant disability and medical concerns. Continual or full medical and nursing support is provided including a high level of assistance with activities including mobility and personal cares. Due to safety and complex care needs, residents generally require a supervised environment and 24/7 Registered Nurse input is provided. Care is available for residents who require hoist transfers, 2 person assists, assistance with food/fluids and who have complex health needs. Hospital equipment (beds, chairs, pressure relieving mattress, etc.) is provided.
- **Psychogeriatric Secure Hospital (Specialist Hospital):** These facilities are similar to Hospital Level care, but the environment is secure. Residents require a secure environment and the skills of staff trained in psychogeriatric care. Facilities provide continual or full medical and nursing support and/or supervision. They manage more severe behavioural problems with 24/7 Registered Nurse availability and higher staffing ratios. Robust diversional

therapy/activities programmes are provided and behaviour management processes are delivered by highly trained staff. This type of care is designed for people with a mental health or dementia disorder who require a high level of nursing care and management of challenging behaviour.

Residents who require palliative care and care at the end of life receive this directly from staff within the facility plus their General Practitioner who are supported by their local specialist palliative care service / hospice. These arrangements are organised locally and generally include the provision of education, clinical advice and back-up. The survey was conducted to explore this provision and the extent of the specialist support available.

Survey responses

ARC facilities provide a range of care options depending on assessed need. Patients with cognitive and/or behavioural problems may require specialist dementia care. The breakdown of ARC facilities from the survey responses was as follows;

- 15 hospital level and rest home combined facilities
- 5 hospital level, rest home and secure dementia rest home
- 1 hospital level, rest home and psychogeriatric secure hospital
- 1 hospital level, secure dementia rest home and psychogeriatric secure hospital
- 1 hospital level and secure dementia rest home
- 1 hospital level and psychogeriatric secure hospital
- 1 hospital level only
- 9 rest home only

The majority of facilities who responded (25/34 facilities) provide hospital level care, 9 facilities provide dementia/psychogeriatric care and 9 are rest home level only.

General Practitioners provide the majority of medical care in ARC. Whilst it is important that residents are entitled to choose their own GP and will be supported to retain a longstanding GP who knows them well should they wish to, anecdotally many facilities report that using a “House GP” can make communication between facility and GP easier and that regular clinical reviews happen in a more structured way. Question 2 on the survey asked about whether facilities had a **House GP or GPs**. 79% of the total respondents answered ‘yes’ to this question. The remainder liaise with each residents’ own GP and do not have a specific “House GP”.

The next question was directed to the rest homes and the secure dementia rest homes and asked whether they were in a position to continue to **provide end of life care** for residents. 94% said they were able to do this. This is a very positive response.

The survey asked about the relationship of all facilities with **specialist palliative care services** for guidance and support when caring for residents with complex palliative care needs. It was extremely pleasing to see that **100%** stated that the relationship was positive.

The next question asked about **24/7 GP access** and this was more concerning with only 44% answering ‘yes’ to having after-hours availability. There was a follow-up question for those who answered ‘yes’ with nearly 50% (of the 44%) reporting that they have to manage with **phone advice only** as their GPs are unable to visit the facility after hours. Just over half of the 44% indicated that GPs **were** able to **conduct visits** after hours if needed. Those who answered ‘no’ to the question of 24/7 access to GPs were asked if they could access primary care via the PHO (such as an after-hours clinic) and

unfortunately 30% of this group answered 'no' to this question as well. The issue therefore of many ARC residents being completely unable to access primary care after hours needs further exploration.

The next question was in regard to the awareness of facilities that GPs may have access to **additional funding to provide palliative care** to ARC residents. Additional funding is available to many GPs across the South Island (through palliative care or end of life subsidies accessible through their PHO) but only 55% of facilities are aware that such funding may be available to their GPs. This may influence the extent to which ARC facilities make use of GPs for their palliative care residents.

The survey asked about access to **education and training in palliative care**. Examples given were the *Hospice New Zealand: Fundamentals of Palliative Care* run through hospices, and postgraduate education in palliative care. Again, the results of this question were very pleasing with 91% saying that staff have access to additional education and training. Only 3/34 respondents answered 'no' to this question.

Facilities were asked about access to **syringe drivers**. Only 2 reported that they have no access with the majority (20/34) having their own in-house supply of syringe drivers. The remainder are able to loan as needed.

Access to **specialised equipment** such as pressure relieving mattresses was the subject of the next question. 94% indicated that they have access to such equipment. This was followed by asking specifically about the **funding** of specialised equipment and 94% said that they had **no** access to additional funding. This means that any extra equipment required for palliative residents is funded through the existing ARC contracts and falls to the facility to ensure that this equipment is readily available.

The next question asked about the ability of facilities to maintain appropriate **medication stocks** to meet residents' need at the end of life. 94% felt that this was possible, with only 2 stating that they were unable to maintain appropriate stock. Both of these facilities were stand-alone rest homes. It is possible that this question was ambiguous, with lack of clarity as to whether the question referred to the "imprest" stock held in hospital level facilities or whether the question was referring to there being sufficient prescribed medication for a particular resident in the palliative or end of life period.

Answers to the question about access to additional **medication after-hours** was much more varied. Only 61% were able to access medications after hours, with a total of 13 being unable to do so. A great deal of additional information was provided to supplement this question giving specific details as to the limitations experienced. Examples were given of restricted after-hours pharmacy hours ranging from closed all weekend, being unavailable on Sundays and other variations in between. Some also mentioned large pharmacy call-out fees. Unfortunately two of the facilities that answered 'no' included hospital level as part of their services, which is concerning and requires further exploration.

The survey then asked about access to information about **advance care planning (ACP)** for residents over and above any in-house advance directives. This is a relatively new area and 64% indicated that they did have access to such information. Most of this is provided through linkages with hospice or palliative care services. The follow-up question asked about whether staff have completed e-Learning packages or other training opportunities in ACP. 14/34 indicated 'no' with two skipping the question. Overall 18 facilities had access to a mixture of online, in-house training or other training opportunities which is pleasing.

Te Ara Whakapiri; principles and guidance for the last days of life (Ministry of Health 2015) is a new national program guiding the management of patients in the last days of life. Nearly half of the

facilities indicated that they have had no access to information about it. This is clearly an area that could easily be addressed through improved communication and education.

The last question was in reference to electronic guidance about providing palliative care and managing symptoms such as **Community HealthPathways** and whether facilities have such access. This is also an area with room for improvement as 26% indicated that they did not have access.

Summary of key findings:

1. It is likely that there is a significant response bias with those facilities that prioritise palliative care more highly taking the time to respond the survey. The results should therefore be interpreted carefully and even though many aspects are reported favourably, it is possible that palliative care provision is more variable throughout the wider sector.
2. The survey reported strong relationships between ARC facilities and their local Hospice/specialist palliative care service. This illustrates a clear commitment to the care of residents at the end of life and is pleasing given the significant input provided by specialist palliative care over recent years. This support has occurred via clinical care of residents alongside ARC staff, education initiatives, telephone advice, collaborative meetings etc. These initiatives need to be maintained going forward and any gaps identified so that all facilities can benefit from timely and effective specialist support.
3. The survey highlighted major gaps in after-hours GP availability and access to newly prescribed medications which is very concerning. This must inevitably hamper the ability of the facility staff to manage imminently dying residents or those with complex needs out of working hours. It is important to note that “usual working hours” account for only one third of the week in total, therefore the majority of care provision to residents is “out of hours”. Consequently this is likely to influence decisions to admit to acute care, which may be against the preferences of the resident.
4. It is well understood that a barrier to good care includes access to equipment which can be costly and falls to the facility when patient is in their care.
5. It is possible that there is limited awareness of additional funding for GPs to visit palliative care patients in ARC. This issue needs further exploration at the PHO level.
6. Numerous opportunities exist to improve care delivered within ARC around access to Community HealthPathways and the new Te Ara Whakapiri Toolkit (recently released). Education and communication strategies could be developed across the South Island to assist with this.
7. Advance Care Planning is a priority across the South Island and needs to be actively supported in ARC to ensure residents wishes and preferences are able to be determined and made visible across the health system. IT solutions, communication skills training and GP subsidies will all be part of the programme of work needed.

Conclusion

ARC is a vital and valued part of our health system regarding the provision of care to people at the end of life. Equity is about ensuring that everyone has access to quality palliative care, wherever they may be cared for in our health system, and that all staff working in ARC have what they need to provide

excellent care to residents and their families/whanau. This includes appropriate training and education opportunities, access to specialist equipment and medication and 24/7 availability of back-up and support.

To ensure equality of service, the interface between GPs, ARC facilities and specialist palliative care needs to be well understood, well-articulated and well resourced.